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ABSTRACT

Summarized in monograph form are proceedings of a 2-day inter-regional training conference held in 1974 on modern dimensions of epilepsy. It is explained that a major conference purpose was to elicit participant suggestions regarding goals and program development, educational and research needs, and funding guidelines. Included are the orientation and opening remarks as well as presentations on topics such as an historical review of epilepsy, current communication problem areas (including attitudes among epileptics and normal persons and dissemination of educational information about epilepsy), treatment needs of epileptic children and adults, diagnosis by electroencephalography and treatment measures (such as anti-epileptic drugs and blood level determinations), community and professional education, employment experiences, available and needed services (in areas such as employment and public relations), legislative and organizational efforts in regard to developmental disabilities, breaking barriers in special education and social services for epileptics, and job placement. (LH)

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MODERN DIMENSIONS OF EPILEPSY

Proceedings of an Inter-Regional Training Conference

held May 21, 22, 1974
at The Rehabilitation Institute of Chicago
345 East Superior Street
Chicago, Illinois 60611

Co-Sponsored by:
Epilepsy Foundation of America
Regions V and VII, Epilepsy Foundation of America
U. S. Department of Health, Education and Welfare
Social and Rehabilitation Services, Regions V and VII
Medical Rehabilitation Research and Training Center No. 20
Rehabilitation Institute of Chicago - Northwestern University

Supported by:

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The organizers of this conference wish to express appreciation to Paula Hamilton and Associates, 63 East Chicago Avenue, Chicago, Illinois for preparation of this monograph.

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INTER-REGIONAL TRAINING CONFERENCE

MODERN DIMENSIONS OF EPILEPSY

Program

May 21, 1974

Chairman, Morning Session

RICHARD ROVNER, M.D.
Director, Epilepsy Clinic
Northwestern University Medical School
Chicago, Illinois

9:15 a.m. *Epilepsy: Historical Review*

LOUIS BOSHES, M.D.
Clinical Professor of Neurology and
Director, Consultation Clinic for Epilepsy
Abraham Lincoln School of Medicine
University of Illinois
Senior Attending Neurologist and Psychiatrist and
Chief of the Neurology Clinics
Michael Reese Hospital and Medical Center
Chicago, Illinois

10:00 a.m. *Epilepsy: Current Communications Problem Areas*

JAMES GORMAN
Epilepsy Foundation of America
Washington, D.C.

10:45 a.m. COFFEE BREAK

11:00 a.m. *Treatment Needs of the Epileptic: The Child*

J. GORDON MILLICHAP, M.D.
Professor, Departments of Neurology and Pediatrics
Northwestern University Medical School
Chicago, Illinois

11:30 a.m. *Treatment Needs of the Epileptic: The Adult*

ALEX J. ARIEFF, M.D.
Department of Neurology
Northwestern University Medical School
Chicago, Illinois

12:15 p.m. LUNCH

Chairman, Afternoon Session

BENJAMIN BOSHES, M.D., Ph.D.
Chairman, Department of Neurology
Northwestern University Medical School
Chicago, Illinois

1:30 p.m. — *Medicine and Machines: Present Status, Future Needs*

ERICH L. GIBBS, Jr., Ph.D.
Gibbs Laboratories
Evanston, Illinois

EPILEPSY FROM THE CONSUMERS' VIEWPOINT

2:30 p.m. — *Community and Professional Education*

JUDITH LESTER
Program Director
Greater Cleveland Chapter
Epilepsy Foundation of America
Cleveland, Ohio

3:00 p.m. — *Employment Experiences*

CAROL LAWLESS
Jewish Vocational Services
Chicago, Illinois

3:30 p.m. — *Services Needed and Services Available*

WILLARD G. NOVAK
Executive Director
Kansas Chapter
Epilepsy Foundation of America
Wichita, Kansas

4:00 p.m. — COFFEE BREAK

4:15 p.m. — *IMPLICATIONS FOR PARTICIPANTS*

Discussion, Questions, Program Direction

ROGER MEYER, M.D.
Regional Medical Coordinator
Social and Rehabilitation Services
Department of Health, Education and Welfare
Chicago, Illinois

SUMMARY

BENJAMIN BOSHES, M.D., Ph.D.

May 22, 1974

Chairman, Morning Session

WILLIAM FERGUSON
Developmental Disabilities Consultant
Regional Services Administration
Social and Rehabilitation Services
Kansas City, Missouri

9:00 a.m. — *Developmental Disabilities: National and Local Relationships*

MARCILE PERRIN
Executive Director
Nebraska Epilepsy League
Epilepsy Foundation of America
Omaha, Nebraska

9:45 a.m. — *Social Services for the Epileptic: Breaking Barriers*

PHILLIP RENNICK, Ph.D.
Chief Psychologist
LaFayette Clinic
Detroit, Michigan

10:30 a.m. — COFFEE BREAK

10:45 a.m. — *Special Education for the Epileptic: Breaking Barriers in the System*

LEE COURTNAGE, Ph.D.
Director, Division of Special Education
University of Northern Iowa
Cedar Falls, Iowa

11:30 a.m. — *Job Placement for Persons with Epilepsy*

DANIEL SINICK, Ph.D.
Director of Rehabilitation Counselor Education
The George Washington University
Washington, D.C.

12:15 p.m. — LUNCH

Chairman, Afternoon Session

ARTHUR PETRY
Regional Manager
Epilepsy Foundation of America
Chicago, Illinois

1:30 p.m. *DISCUSSION*

THOMAS ENNIS
Executive Director
Epilepsy Foundation of America
Washington, D.C.

WILLIAM FERGUSON
Developmental Disabilities Consultant
Social and Rehabilitation Services, Region VII
Kansas City, Missouri

ROBERT VOGT
Developmental Disabilities Consultant
Social and Rehabilitation Services, Region V
Chicago, Illinois

Welcome and Orientation

Don A, Olson, Ph.D.
Director of Training
Rehabilitation Institute of Chicago
Chicago, Illinois

I want to welcome you all to this conference today, and also to our new building. We are planning many more educational and research programs which will be of interest to a wide variety of people, both throughout the region and also on a national level.

Mr. Petry and I, in conjunction with the Social and Rehabilitation Services of Regions V and VII, have finally managed to put this meeting together. It has been very difficult; it seems that the existing interest in epilepsy does not produce much constructive action.

The idea of the conference was to get a small number of people together and develop a monograph from the presentations and discussions that will take place over the two-day period. This will be disseminated in the two regions, and also in Washington, in answer to a request for information on the results of the conference.

Apparently there is some interest on several levels but there is no direction as to what should be done and what should be funded, therefore what we need from this group is some guidelines as to the fundable needs and suggestions in terms of goals and program development. We are doing this because nobody in the Federal Government nor in some of our regional organizations is doing it as far as we know. The people we have brought together are experts in their field but are very willing to listen so we hope you will feel free to provide as much input as possible.

Now I will turn the proceedings over to Dr. Rovner who is Chairman of this morning's session. Dr. Rovner is Chief of Staff and Consultant in Neurology at the Rehabilitation Institute and is also Director of the Epilepsy Clinic at Northwestern University.

Opening Remarks

Richard Rovner, M.D.

It is a pleasure to start off the program in epilepsy for the Rehabilitation Institute. We are trying hard to integrate our university epilepsy program with rehabilitation and the Institute's move to this new building nearer the Medical Center will be a big step forward.

First on the program is Dr. Louis Boshes, who is Clinical Professor of Neurology and Director of the Consultation Clinic for Epilepsy at the Abraham Lincoln School of Medicine, University of Illinois, a larger clinic than we have at Northwestern. He is a former Northwesterner and Senior Attending Neurologist and Psychiatrist and Chairman of Neurology Clinics of Michael Reese Hospital and Medical Center.

Louis Boshes, M.D.
Clinical Professor of Neurology and Director
Consultation Clinic for Epilepsy
Abraham Lincoln School of Medicine, University of Illinois
Senior Attending Neurologist and Psychiatrist
and Chief of the Neurology Clinics at
Michael Reese Hospital and Medical Center

I am not truly an apostate from Northwestern for my spirit is still here although bodily I am officially at the University of Illinois. I learned about epilepsy the moment I walked into Northwestern. I have never forgotten it because Northwestern really has a heritage of epilepsy, and you "live", "breathe", "sleep" and "eat" epilepsy while here. I doubt if there is a graduate from Northwestern Medical School who does not know what the implication of epilepsy is, what it means, including its impact on others. There are people in the student body who have seizures, and certainly many in the Faculty. I take care of them and consider my management only that of any other symptom in a human; I have treated animals too.

Not too long ago at a dinner party I sat next to a well-known priest, and before long he and I were quoting the Bible on epilepsy, not only the Old Testament but the New Testament. When I came home I went to the Bible to see how correct we were and found we were both rather accurate. Better than that, I would refer you to a book by Timken of Johns Hopkins, which is truly the "Bible" of "Bibles" on epilepsy. It is called "The Falling Sickness," and it is extremely well researched and beautifully annotated.

If any of you in the audience intend to remain in Chicago for a few days, I recommend you go to the northwest side and stand in line in front of the Gateway Theater where they are showing "The Exorcist." After about two hours' wait you will go in and get your education the hard way in terms of what is going on. Author William B. Blakeley has really brought epilepsy to the fore in certain senses of the word. To date, six separate people have come to me to tell me that their Spiritual Fathers have said to them, "Yes, I know now what causes your epilepsy. You're absolutely possessed. Demoniacal possession by something is the reason you have your seizures. I'll take care of it, forget about the clinics." It is as bad as that.

I would like to describe to you this morning what has happened historically in terms of epilepsy. Epilepsy started a very long time ago and I'm going to take you on a mythical grand rounds through its history. There existed ignorance and fear all the way through, fear and prejudice, prejudice and stigma. We are going to explore the myth, and we are going to explore the facts. We are going to talk about the law and society. Then we are going to end that myth and show you how that individual who has seizures is still looked upon not as a first-class cicizen, but as a second-class citizen.

In the code of Hammurabi, who was at that time King of Babylonia, there were many laws affecting the people and as far as these people were concerned, there were validities to the laws because they had testimony. They had testimony not only from people, but also from those around them. They had testimony of their so-called self-styled courts, in such a way that this illness was ascribed to many things, among them wickedness, and divine retribution. It was a phenomenon that certainly had a satanic influence.

Many of you probably read The Spokesman, which is printed by the Epilepsy Foundation of America and know of the singer, Pat Boone's activities in the field of epilepsy. Recently I was at his home and he showed me his swimming pool where he baptizes people against epilepsy. It seems that after he returned from his father-in-law's funeral, Red Foley of the barn dance music, Pat and his wife, who is a delightful person, went on a religious kick, and from that came an article which was printed in a popular magazine. What he said was so detrimental to our cause in the understanding, if not the management, of seizures. Eventually there was a retraction and an apology written by Mr. Boone. But still he said, "In the name of the Lord," and he has still not let go, because he has told me as much.

In the recent past, another illness has come to the fore, called Gillē de la Tourette Disorder, which is a syndrome named after the man who took care of an aged Marquessa (actually he just came in at the end and had his name placed on this illness). I know a patient with this disorder who is a small boy in the back room of one of our psychiatric hospitals. He has little twitches of the face, little convulsive movements, and he echoes everything that is said to him. He swears better than anybody I have ever heard. These patients, children, young adults, adults and older people were treated in many different ways until recently when a new drug called Haldol came forth, not in this country, but in France and England, and it has dramatically helped these individuals. The story of this syndrome also hit the press. All it takes is just one man to interview us; he is syndicated to a couple of hundred newspapers and the story hits every magazine. When it hit the Reader's Digest with perhaps 15-20 million readers, I was overwhelmed by letters.

The same thing happened with "The Exorcist." I had an interview with one of the science reporters of a newspaper here in Chicago, and since this man is not of the caliber of some of the others, I asked to see the proofs. I did not receive them and when I read this article on exorcism versus epilepsy, I did not recognize it -- I asked, "Who wrote it?" But, unfortunately, my name was after it.

Epilepsy has been called the "sacred illness". In Peru in the olden days, they would make a hole in the skull to "leak" out the evil spirits. When I visited Peru I was taken through some of the museums to see some of the beautifully healed openings in the skull. The so-called "sacred illness" always had a certain amount of divinity associated with it. Even today, as a modern method for the management of seizures, there is still surgery of the skull being done, and opening and closing a skull is a very dramatic and non-realistic measure, but somehow seizures stop.

I want to say categorically that we are not dealing with a disease in spite of the fact that I used the words "sacred illness". "Epilepsy" is a word which means to seize upon, to control, to catch, to overtake, and it is taken from the Greek verb; it does not mean an illness.

I have a woman in one of my clinics who calls her epilepsy attacks "athletic" attacks, and this is not a bad description because there are running attacks and we see and read a lot about this in the old civilizations such as Mesopotamia. We see and read about individuals who suddenly have their heads turned to the left and their arm goes up. This is what is called an adversive seizure. Or an individual who is talking to someone suddenly turns blank, and he has had a seizure, or the blinking of the eyes. This is Petit Mal.

In one of the schools near here, I take care of a Dean who has petit mal seizures. He used to have five, six, seven hundred a day. Now he is down to three or four a day. When he is talking to students and giving a lecture and he has a seizure, his line of thought stops. It is his habit to turn to the first student in front of him and say, "What did I say?" If this one cannot answer, he goes to the next one, and the next one, until one says, "Well, Dean, you just said so-and-so." To which he replies, "Of course I did." This is his cue and where he picks up. He handles the seizures very well.

Regardless of what reading we do and in what literature, we find that most of the time it was felt the condition emanated from the brain, because from there come psychic phenomena and processes both normal and abnormal.

The presence of a god or demon during an attack gives the attack a certain amount of social significance. In Roman days when somebody had a seizure perhaps during the city council meeting, that was the end of the meeting for the day. They adjourned it immediately, because it was felt that this individual was unclean. What happened was that many of the other members within the Forum would spit upon the person who had a seizure because this was one of the ways of eradicating the demon that that person emitted. In fact, some of our grandmothers used this means sometimes to ward off the devil; even in 1974 it is still used. It was felt that that individual had contagion, and an individual with seizures was always felt to be harboring something that he should not have.

Many a time an individual on the way to a seizure, during his aura, which means to blow upon, to blow over, had sufficient time to cover his head. Many people who had seizures always carried something with which to cover their heads, possibly a cloth, and from this has come the custom of covering the head or blindfolding during an execution, whether it be by hanging or by the execution squad.

Epilepsy was also attributed to as a weapon, and it was used in various ways during rituals. There were many rituals that were used not only in managing the epileptic but also punishing him. There was treatment during the ritual during which many unusual formulae were used, such as the drinking of blood of gladiators, gnashing of the teeth, or eating of the teeth. Many a time this was so revolting to the one who was being

perhaps initiated into something that he himself had a seizure, regardless of whether or not he was in the habit of having seizures.

There were many other formulae that the pharmacists concocted, such as skins of lizards, crocodiles, genitals of a hare, testicles of hippopotamus, hooves of horses or mules, and parts of chickens. Now, all of these substances were supposed to have powers and that is why they were given to the individual with seizures. In 1973 there were still "magical powers" being used in the management of epilepsy.

In traveling through Europe, particularly through some of the cathedrals or religious areas, we see many masterpieces which have the divine involvement concerning an individual who has a seizure. The angels come forth, people are very worried and concerned and as a result there is a certain amount of divine interest.

In Nigeria, some of the modern methods of management of seizures include the wearing of copper amulets such as those worn for the alleviation of arthritic pains. In Nigeria an individual may be scarified on the shoulder because he is wearing a copper amulet for the treatment of his seizures. A little baby who during his seizure and afterwards has coma, will have hot sticks or coals put at the soul to awaken him. Finally, to cure everything, the patient goes to see a doctor who uses an electrocomputer and he takes care of seizures. He is certainly ahead of most of us. It is my opinion that by 2001 A.D. we shall be doing such things as examining throats by computer, reaching a diagnosis by means of a computer read-out.

There are many climatic factors which involve seizures. It is written, not only in the Bible, but also in some of the history books that there are seizures which occur in cold countries and seizures which occur in warm countries. Actually they occur everywhere in the world.

Along with the matter of climate comes exercise, and one of its greatest exponents was Julius Caesar. He was not only a great army man, a great commander, but he was an understanding individual in terms of his legions, and he always gave them good care after they returned from campaigns, not only with material gifts of land, but also taking care of the legionnaires who had seizures. He gave them a very well indoctrinated, orderly set of exercises, and they just had to take these exercises. He knew that they had what was called aurae, because they would tell their company commanders that they had premonitions of seizures.

In discussing aurae, some people will say they have a bee buzzing around. Another may say little goblins float around his head. Another will say that the aura to his seizure may be any kind of activity or maybe he hears music. I have seen individuals who had seizures brought on by music, and two of them had seizures brought on by the Beatles.

We were involved with Dr. Francis Forester of Madison, Wisconsin, on a very unusual type of seizure patient. He had seizures due to listening to only one song, "Stardust," played by the late Glenn Miller's band. There are about four hundred editions of "Stardust," played by symphony orchestras, quintets, quartets, solos, et cetera, but of all of them, he only had seizures to this one. As a result this man was

deconditioned over a period of some four thousand hours so that the notes of that song were piped into another set of music, and he no longer had any seizures.

In the fourth and fifth centuries the same kind of ignorance, the same kind of stigma, held forth, but at this time they began to realize that seizures were due to two situations -- one, trouble in the skull when it was closed, and two, trouble in the skull when it was opened. It was realized that there was illness within the skull, that is, infections, inflammations, tumors, blood vessel diseases, and other disorders. If there was trouble when the skull was opened, then this meant trauma. Galen was one of the most important men to state that this indeed was happening.

Historically, there were some very great people who had seizures, and they were not limited to individuals with or without certain levels of intelligence. These individuals included Alexander the Great, Buodha, Dante, Dickens, Dostoevski, Handel, Samuel Johnson, Guy de Maupassant, Napoleon, Alfred Nobel, Paganini, St. Paul, Cardinal Richelieu, Sir Walter Scott, Shelley, Socrates, and Tolstoy. In the present day there is Hal Lanier of the San Francisco Giants, Gary Howlett, the ice hockey player, John Lowenbach, the sky diver, who is fighting everybody because he still wants to come down in his parachute, and John Considine from "Marcus Welby."

Let me very briefly discuss the management of seizures. There are drugs. There is complete abstinence from food or drink. Drink is very important because people who drink too much fluid develop what is called edema of the brain. It is for that reason we cut down on fluids particularly in pre-menstrual women, because seven to ten days before a period seizures are more prone to happen to a woman.

There are several major things that people with seizures should or should not do. One, they must take their medicine reliably and regularly. Second, it is extremely important not to become fatigued. We find fatigue in a great number of individuals who should not be having seizures. The third thing affecting seizures is gastrointestinal function; constipation is one of the most common causes for seizures. Lastly, their fluid intake. We usually tell them what they should imbibe in number of ounces of water, milk, soup, coffee and tea. In the summer time epileptic numbers rise in great profusion -- a coke, for example, is 16 ounces. Any kind of alcohol will cause seizures.

The religious individual came into importance as time went on because he realized that he had a great effect upon individual seizures, so they came to him in great multitudes. Once again those concoctions I mentioned earlier were also offered to the individual with seizure by the man of a certain faith, and with them came a great deal of prayer. This is still being done in numerous countries, particularly in those tropical countries which I visited on some of my tours as an Ambassador of the International Bureau of Epilepsy, where I saw what a medicine man will do to remove seizures from an individual. Associated with some of these is something called "lunacy". The moon plays a very important role in seizures, and that is where the word "luna - lunacy" comes from. There is a time of the month which is dreaded not only by the individual who has seizures but also

by the person who takes care of him.

At one time in history the individual with seizures had a great deal of sympathy, of empathy, and he became not only a person with seizures but was also recognized as an individual who was a beggar. Accordingly he donned beggars outfits and everybody gave him alms because he was a person who needed these funds to buy special medications. Soon, as with everything else, everybody else got into the act and people without seizures were doing the same thing and getting alms, and very soon it was stopped.

Around the 16th and 17th centuries they began to relate epilepsy to mental illness, and soon the combination of schizophrenia and epilepsy existed. More than that, into so-called insane asylums were placed not only people with epilepsy and with seizures, but invariably the prostitutes. It is difficult to believe that in 1968 when our immigration laws were reviewed, there was still this trilogy: epilepsy, schizophrenia, and prostitution, preventing people from coming into this country. Now the laws are changed and all can enter the country with little difficulty.

The art of France contains many examples of individuals in the process of having seizures, one pictures an individual in an arc. There it was called the "maladie mentalis," yet it was not a mental malady; it was definitely a seizure.

There was a great French neurologist named Charot. He was a magnificent man who made his rounds with a tall silk hat and a frock coat and the ladies really went for him. As he went on his rounds, stopping here and there, the women would do all sorts of things to gain the old master's attention, epilepsy therefore developed a sexual connotation.

A new era started in 1961 with the name of Hughling Jackson, who worked at what is the mecca for all of neurology. People go from all over the world even today to the National Hospital, Queen's Square, in London, to learn about Neurology, within the scope of which is epilepsy. It has been said that the history of the world, the history of medicine, is involved in only one word, and that is "epilepsy".

There were many men who were scholarly, who knew about epilepsy, but Jackson in particular started the new look because he made a clean-cut definition of it, particularly of what we know as the Jacksonian seizure. A Jacksonian seizure of the face involves a little twitching, or a twitching of the hands. We watch to see whether it is limited to just one side of the body or whether it moves up and finally becomes a grand mal seizure. Many of you as educators have probably seen some of the movies which have been distributed by the Epilepsy Foundation of America showing just what a seizure is.

I recall many years ago something that took place that was a great deal stronger than showing a movie. A young couple about to be married went to one of our famous neurologists, and the young man said, "I'm going to marry this young lady and she has seizures. How will I know what a seizure is, and what shall I do about it?" Since there were no movies like "Modern Aspects of Epilepsy" at that time, this doctor gave

the young woman an electro-shock treatment, and with this the young man watched a perfect grand mal seizure. As a result he knew exactly what to do and how to do it.

During the war I worked with the Marines. Many of these young men had not revealed that they had seizure because that would have kept them out of the service. The men told me about the behavior of one of their friends. Since I had a little black box with me, the electro-shock machine, I would sometimes give this man a treatment two or three days before he had his seizure. I would explode or detonate him, and even with a single treatment, he was himself after a day or so, and he did not have a seizure.

In this country, our understanding of seizures began about the middle of the 18th century. They existed even in our first family, Roosevelt had small seizures, Calvin Cooledge had small seizures, Winston Churchill had small seizures; these were never recorded.

The real management of seizures began in about 1857 in an insane asylum in Vienna. I use the word "asylum" because in it as well were the three groups I have already mentioned, the individual with seizures, the schizophrenic and the prostitute. It was felt there was just too much "promiscuity" going on, so bromides were given to these inmates. In a meeting in London many months later, one of the men described his results with bromides given especially to young women, another described his experience giving bromides to people with homosexuality or for masturbation, and each felt something good happened. As a result bromides were born. They became the treatment of choice; here at Northwestern we used bromides by countless gallons. I cannot tell you how many people I gave bromide poisoning to, but we stopped the seizures. Some doctors are still using them from time to time.

We had bromides from 1857 until 1911 when a drug called Luminal was born; it is also known as phenobarbital. This drug was used so successfully for seizures that in 1920 it was brought to this country by the later Dr. Julius Ryker, who was the father of the present Dr. Roy Ryker, Sr. Now we had two drugs, bromides and phenobarbital.

In 1937, Tracy Putnam, H. Houston Marett, and William Lennox worked on a series of drugs. (Actually, the work was done by a girl named Dorothy Fisher, who became the wife of the late Robert Schwab.) They ran almost seven hundred punctures until they came upon a drug called Dilantin. In 1937 at the American Neurological Association this drug was described as being used to stop seizures electrically caused in animals, and in 1938 it was described at the American Medical Association as a drug used for control of seizures in humans. That is how Dilantin was created.

From 1938 to the present time we have had almost thirty drugs in use. Unfortunately there is a tragic side to drugs when there are side effects. We are hoping that one day soon we will have one drug which will control seizures and which will produce no somnolence, and will have no other side effects. This would be the ideal.

When you read in the newspaper that someone died and the cause of death was epilepsy, about 100% of the time this is wrong. We have status epilepticus, which is a severe medical emergency, but I am certain that Dr. Rovner has never lost one of his patients, and nor have I, because of our astute management at the present time. So if someone is said to be found dead during the night or in the apartment due to epilepsy, this sets our movement back many dozens of years.

The late Dr. Hans Berger was the father of electroencephalography but unfortunately did not live to see his greatness appreciated. I was in his laboratory to see how he created his first electroencephalograph with two twenty-ton blocks of concrete, with wire between them. Those of you who go to conventions now see these sophisticated little boxes which take up to sixteen channels.

Other people historically involved with epilepsy, as well as Dr. Berger and Dr. Hughling Jackson, include Dr. and Mrs. Frederick A. Gibbs, both still extremely active. Mrs. Eleanor Roosevelt was very active in helping to further the epilepsy movement. The Epilepsy Foundation of America, as it is known today, came about through the efforts of Mrs. Charles Markham. Mrs. Ellen Gross is the queen as far as epilepsy is concerned, not only here but everywhere in the world and seldom misses a meeting on epilepsy.

A word about epileptic colonies. Some of us have had the opportunity to go to Europe, to places like Meer-en-Boche in Holland, to see seven, eight, nine hundred people in an epileptic colony where even the teachers have seizures. There are colonies also in Norway and in Denmark. I helped set one up in England and we have one in America. Certainly we hope to have others where we can really do some good. The area planned, part of it is in fact already functional, is in Leesburg, Virginia. The people in the colonies are patients, but they also work for their keep.

Eventually most of the major areas of epilepsy, the lay group, those doing work on seizures, those furthering the cause, came together and formed the Epilepsy Foundation of America. Right here in Chicago we have an arm of the Epilepsy Foundation of America, and I hope that those of you who come from a distance will have the opportunity to visit our offices.

DISCUSSION

Member: You mentioned that hopefully there would very shortly be one drug. Is there anything that has been discovered that is being worked on?

Dr. L. Boches: In the last seven years the FDA has not permitted one drug to come forth. I have four drugs in my laboratory that we have worked through beautifully which have so much promise. Unfortunately nothing has happened. Yesterday in the latest issue of Neurology the first lead article was on Tegretol, a very unusual drug. There are four major drugs we use: Dilantin, phenobarbital, Ironton, and Tegretol. Tegretol had an unusual birth. It was first described as an anti-convulsive. It was tried as an

Dr. L. Boshes: (cont.) anti-convulsive, but somehow or other it was just not run as carefully or as sophisticatedly as we normally do, so they abandoned it. Then it was used as a psychotropic, an anti-depressant, and again it was not researched properly. But some astute observers noted that if people had severe pain in their faces, this drug worked beautifully. I am happy to say my group and I were one of the four in this country that did the work on Tegretol for facial pain.

History then turned around and it went back to being used as an anti-convulsant, and here at Northwestern, Dr. Alex Arieff and Dr. Manual Mier, who is presently in Florida, did one of the monumental papers which is quoted in the article. Now there are hundreds of papers on Tegretol. and it is used everywhere in the world except in the United States. But I have about 1,400 patients on it; they all know the side effects, and they are all taking it and are very thankful.

The ideal drug will some day be completely anti-convulsive, completely non-sedative, completely non-toxic. Where there are too many drugs, there is something wrong, we need only one.

It is my opinion that people with seizures who have other problems associated with them should be congregated together where they can get the total approach in the same way as the Rehabilitation Institute of Chicago has consultants in every discipline in medicine. If it is possible to take X number of individuals who can be managed better, who can be put into control faster, who can go into a useful life, then a place like Leesburg is an area of choice, or perhaps a place here in Chicago.

For example, through the University of Illinois we are building satellite clinics. It is my hope to have satellite groups all over the state, even if we visit these areas with a bus, doctors, nurses, social workers, psychologists, an EEG machine and a pharmacy.

Member: Do these people stay at the centers or do they go there for treatment?

Dr. L. Boshes: I would call it a diagnostic and treatment center. In Meer-en-Boche or Heemstedt outside Amsterdam the people live there, they are part of the community. Some stay six months, some a year, some two years. They stay long enough to know that they are in good control and can go back into their communities and do what has to be done. There is absolutely no stigma attached to it.

Dr. Rovner: This was a very inspiring talk and I think that by looking over the history of epilepsy in particular we can see what real massive ignorance there has been in the past and what traditions we have to change. It really shows the tremendous undertaking we, as educators, are responsible for.

Epilepsy: Current Communications Problem Areas

James Gorman
Epilepsy Foundation of America
Washington, D.C.

My background is not in the medical field, it is not in the epilepsy field; I am merely a communications person. I became involved in the advertising/public relations field after I got my master's in New York, so originally I am a businessman. When I was in Chicago years ago I worked for a number of years for the Chicago Daily News, and that was an experience I would not trade for anything except the kind of work I am doing today.

As I understand it, one of the things you are trying to do is to establish a priority, or a number of priorities, as to where you should use your time and your money. I am here to promote priority of communications. Perhaps I can be more objective than many people who have been involved in epilepsy for all of their lives. It is very clear to me that the question is, how do we get people who have epilepsy to accept it, to live with it, and those who do not have it, to accept it and live with it? That is a communications problem.

Communications must be a two-way street. It is not just me, or the Epilepsy Foundation, churning out barrels of material, although we do, and it is good material, for people to use or read or look at, but it is also reaching out to those same people, whether they are people who have epilepsy or people who are parents of children who have it or people who work with it, and saying, "How do you see it?" It is an advertising, a public relations, a communications technique. It is not how I see it, it is how the person out there sees it, and how I communicate with him in view of his perception of the problem, bearing in mind that the perception of the problem is not always the same as the problem itself. That is what we have to learn to deal with.

I would like to tell you the kinds of questions we have asked of people in order to learn what to project. In this respect, we are really employed in social research.

In terms of statistics, we must understand that no figures are absolute. Sometimes people hang up on a difference of two or five percentage points, and one can not do this, because social research is not an exact science. If you will take the broad picture you will see that those things most important to the people are employment, acceptance of themselves and self-confidence, medical problems, and public attitudes.

It is important that we characterize whether we are talking to adults who have epilepsy, or to parents of children who have it, or to children who have it, or to those who employ people with epilepsy. The two biggest groups of questions in this area of communications are "job" and "social".

The questions we have asked include the following:

1. What do you feel your greatest problem is? This question is directed toward adults. We want to know what they believe to be the problem, not what we think it is.

2. What problems have you had because of epilepsy?

3. Have you ever been turned down for a job because of epilepsy? The answer is surprising: Yes, 46%; no, 43%.

   The question we did not ask was, "Did you tell them you have it?" If the person did not tell them he had epilepsy, obviously he was not turned down; sometimes when we receive the results of a survey, we find out what questions we should have asked.

4. Have you ever been dismissed because of a seizure? Answer: Yes, 33%; no, 66%.

   We have to relate these figures, and with data processing and computers, "massage" the figures, relating this question to the previous one,"Have you ever been turned down because of epilepsy", and correlate the two. It splits out, about half and half.

5. Did epilepsy influence your occupational choice? The answer again is surprising: Yes, 44.9%; no, 55.1%.

   I wonder whether we asked the right question there. I wonder whether the person said to himself, "I really didn't have a choice. I couldn't work on bridges, so that was not a choice."

After having done that research, we did a more recent, continuing survey with parents of children with epilepsy and people who had it. We had about eight hundred people on our mailing list out of EFA in Washington developed from thousands of letters we receive every year from people who ask us about the social problems of epilepsy.

We asked, "What kind of nationally known figure do you believe would best represent the epilepsy movement?" Overwhelmingly they chose a physician, next, an athlete, and next, an actor or actress.

We asked, "What do you consider the best description of epilepsy?" and overwhelmingly they said, "An electrical overload in the brain." That is how they see it and therefore that is the best way for us to refer to it with them.

We asked, "What would you compare epilepsy to?" Overwhelmingly they replied, "A short circuit." This obviously relates to the electrical overload in the brain, and it comes up time and time again.

We asked, "What do you consider the worst description of epilepsy?"

Three replies came out about even: 1) Falling down a dizzy, dark well, 2) a disease, and 3) a falling sickness. They do not see it in relation to falling. An earlier speaker mentioned that one of the best books on the subject referred to "the falling sickness" but that was a long time ago, and people today do not seem to see it that way for themselves.

We asked, "What word or words do you object to in written material about epilepsy?" Eighty-seven percent said they objected to the word "fits." Everybody in the movement at one time or another has used the word but people who have epilepsy do not like it.

We asked, "Do you believe epileptic seizures should be shown on TV?" Seventy-one percent said yes; they want people to know what it looks like. I think the reason for this is because they do not want people to be frightened, and they consider that if one has seen it, one is not as afraid. To be sure that this is the reason, we have to ask "Why?" in a future study.

We asked, "What do you believe the public reaction would be to seizures if they are shown on TV?" The two main comments that came out were 1) that the viewer would acquire an understanding, he would begin to understand more about the problem, and 2) that there would be a combination of feelings: horror, terror, revulsion, pity, and acceptance. It seems to me that the person with epilepsy is willing to gamble on the public having these feelings in order to gain understanding.

We asked, "What should our public messages emphasize?" They cited three things: the problem, the normal aspect of epilepsy, that is, "I have a problem, but I'm normal", and the fact that there is successful treatment.

It strikes me from this data that the people who have epilepsy or who have children who have it are ready and willing to be quite open about this whole problem. Therefore, we should begin to talk about it quite openly; they want us to, they want to be understood.

It bothered me to raise such questions as horror, terror, revulsion, and pity, but it does not bother them, because they have been through it, and they are saying, "Let them know that, but let them understand."

The whole point in this kind of survey is to find out what we should say and how we should say it so that we can best do the job for the person for whom we have to be the advocate.

Another step is dealing with normal people. What is their reaction toward the person with epilepsy? If we can bring that data together with the other data, we can begin to put together in all different forms of media the kind of story that can be told for the person who has epilepsy to the person who does not have it. That is good communications and sound management, which is what communications today is to a great extent.

We have really two roles in the information and education field, and everyone here shares those roles, and all our chapters share them. One is on the negative side; we must constantly be a defender when we come

across something incorrect, in print, on television, or in a talk, wherever we are. We must constantly say, "That is wrong; here is the fact." That is what much of our material is designed for, to provide the kind of fact that is needed. We often see something wrong and we intend to do something about it but we rarely do. I urge you to pick up the telephone and call the person who wrote it, or call his editor, and correct the information, otherwise it will be perpetuated.

The other role that we all have, although at different levels and with different audiences, is an advocacy role. We must go to people who are able to sway public opinion, whether they be in the media, or in politics, or whether they are people of influence in a city or town. We must say to them, "We would like you as a person who has a real opportunity to influence public opinion to know the facts about epilepsy. Please learn them because you can influence other people."

It is a responsibility we all have. I know that both these roles come into play with the media, television, newspapers, radio, magazines.

As I know from experience, the members of the press are under tremendous time pressures; they are always fighting severe deadlines. Then there are the competitive pressures. There is a constant ratings war going on between the three or four stations in a town on their news. They get their advertising by their ratings and the size of their audience is therefore very important to them. Therefore, they are always tempted to do something with a story that will make it a little more exciting than the other man's. This is a fact of life. They have a huge flood of information coming across their desks and they pick only those things that are most exciting and most important and which will catch the eye. However, I have never met a journalist or an editor who, when one had the opportunity to spend a few minutes with him and tell him the facts of epilepsy, did not say, "I never knew that. When I need help in this field, I'll call you." They want to be accurate, but they do not know the facts, and no one has ever told them. They do not want to print things that are not right, and they are willing to be corrected so long as it is done gently and forthrightly and with understanding.

One of the things I would urge upon you today is that at every level of operation of the epilepsy movement, national or regional, within educational facilities or in chapters, or on the basis of the individual, it is as important today to have an expert in public health education as it is to have a legal expert or a medical expert at these various levels. We still have not found a cure for epilepsy, and that public information person who knows the media field is going to be able to help people cope with it until the cure is found. This person is not the equivalent of a medical doctor, but his function is just as important.

The Advertising Council, the national group, and the National Health Council have put together a campaign of two hundred health careers listing all the kinds of people who are essential to the health movement. One of them is the public information or communications specialist. They are encouraging this kind of interdisciplinary work and I urge you also to encourage it in your own areas.

As you are well aware, the new Developmental Disabilities Bill which is now under consideration has a specific section in it where it says money can be obtained for public information programs. To my knowledge, this is the first time that intangible area has ever been brought into it and I urge you to set up a program and get the money to run it.

In government relations, it is extremely important that your communications be strong with people at every level, state, county, city, and federal. EFA has been instrumental, with the Dominick Resolution in the Senate and the Kyros Bill in the House, in developing a national plan for epilepsy. It has been essentially instrumental in working with NINDS. The same thing is happening at state and country levels. This must continue and must be a priority.

The big question then really is, how do we manage today? Dr. Boshes talked about ignorance and fear and prejudice and stigma. In my opinion, we can overcome ignorance with knowledge, or at least we can fight it with knowledge. The more one knows, the less ignorant one will be. We can also fight fear with experience. Exposure to a problem mitigates fear of that problem. This is true of handicapped people; we can overcome prejudice with firsthand contact. We can see this in our relationships in this country between whites and blacks. The problem is not what it was ten or fifteen years ago, because whites have lived next to blacks, have worked with them, and are not as fearful or ignorant about them. Lastly, when a person is personally accepted for what he is, stigma disappears. This is equally true of a handicapped person in a wheelchair as a person with epilepsy.

This is what communications is trying to bring about. It happens at a personal level and all the way up. I would urge you, even entreat you, to make communications in your particular district or facility one of the top priorities in this whole fine movement of epilepsy.

DISCUSSION

Chairman Rovner: I read an article in the New York Times suggesting that attitudes toward epilepsy are changing. I'm glad to see that the epileptic patients feel that an open discussion of their problems is in their interest too, because I think this is what we have been doing, putting seizures on television. The question is, is it working? Do you have any data to support this?

Mr. Gorman: This was an article that ran not only in the Times but in a number of papers across the country. We did not authorize nor pay for it, but every now and then Gallup drops into a study questions about people with epilepsy and attitudes toward them. This is the most recent one and compares the present day with 1949. I would prefer to see a much closer comparison in terms of time to see what kind of progress we have made. The results do show that there have been tremendous improvements in the attitudes of people toward people with epilepsy, but I would certainly expect this in twenty-five years.

Member: Why do you think people are really afraid of seizures or looking at a person with seizures?

Mr. Gorman: The doctors tell me, and I refer specifically to Dr. George Goldin, a sociologist in Boston who works with us to a great extent, that they believe the people with epilepsy frighten the person watching when they go out of control, that the loss of bodily, or what seems to be mental, control is at the heart of it. And the fear on the part of the person is, "I don't know what they are going to do. I don't know if they will hurt themselves. I don't know how to handle them." Again, Dr. Goldin says, "Fear causes prejudice." In my own area, non-medicine, I would accept that. I have seen fear in crowds of people erupt into riots because they did not know what the other one was going to do.

Member: What is the interpretation of the EFA in regard to the definition of epilepsy, as found in the DD definition?

Mr. Gorman: I would like to see the exact wording before I would comment, however, Dr. James Watson of Portland, Oregon, on the Board of Directors of the EFA, testified before the people putting that bill together, along with other societies that are involved with the brain, and I would expect that he is aware of the definition.

Member: I would gather that would be relatively important from the standpoint of who does what. Are you talking about those who are more involved? So far you are talking basically about those who are "of normal intelligence" who have epilepsy. I am wondering how that relates to those who are more involved and would fall more within the definition of DD.

Member: I am on the National Advisory Council, and the definition is not categorical and does not define epilepsy <u>per se</u>. It just defines what mental disbailities are.

Member: Does the National Council interpret epilepsy as being part of DD?

Member: The reason epilepsy and cerebral palsy are included in the first place is because it goes "across the board", and many people who are mentally retarded also have seizures or cerebral palsy, and vice versa, and there is a neurological base to it.

Member: Then what you are saying is that the basic key is mental retardation?

Member: It has been difficult to get the concept of "across the board" but it is developing.

Member: Do you not think the intent of the legislation was to try to provide services to the individuals in categories who were severely disabled who were not being provided services before?

Member: That is really a matter where the Federal Government has a particular definition for severely disabled or handicapped, but individual councils are taking a look at it according to the needs of their own communities and defining it in their own terms. For instance, educably mentally retarded children are really not to be included, and yet in some of your planning you have groups offering services to that population.

Member: As I recall, there is a legal definition of any of the categories in the DDSA legislation, and the answer would be rather an offshoot answer. The law as written in that Act does not define any of those neurological disabilities or disorders. You have to look at it from the other end of the definition. In other words, I do not believe epilepsy is defined in the sense of your question in the legislation. I think you have to interpret what is included in epilepsy. That is quite a different question.

Treatment Needs of the Epileptic: The Child

J. Gordon Millichap, M.D.
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Epilepsy is principally a disorder of childhood; 90-95% of patients with epilepsy will have the first seizure before twenty years of age.

Therapeutic classification of seizures of value in practice is as follows: grand mal, focal motor, petit mal, psychomotor, and infantile myoclonic, each of which has a distinctive EEG pattern.

Table I

A THERAPEUTIC CLASSIFICATION OF THE EPILEPSIES IN CHILDREN

Seizure Patterns	Most Specific Therapies	EEG Correlates
Grand mal and focal motor	phenobarbital Dilantin Mysoline Tegretol	spikes, sharp waves, slow waves
Petit mal	Zarontin Diamox Tridione	3/sec. spike-and-wave
Psychomotor	Mysoline Dilantin Tegretol	temporal lobe spikes, sharp waves
Minor myoclonic and akinetic	Valium Mysoline ketogenic diet	polyspike-and-wave, 2/sec. slow spike-and-wave
Myoclonic spasms	ACTH Valium Mogadon Clonazapam	hypsarhythmia

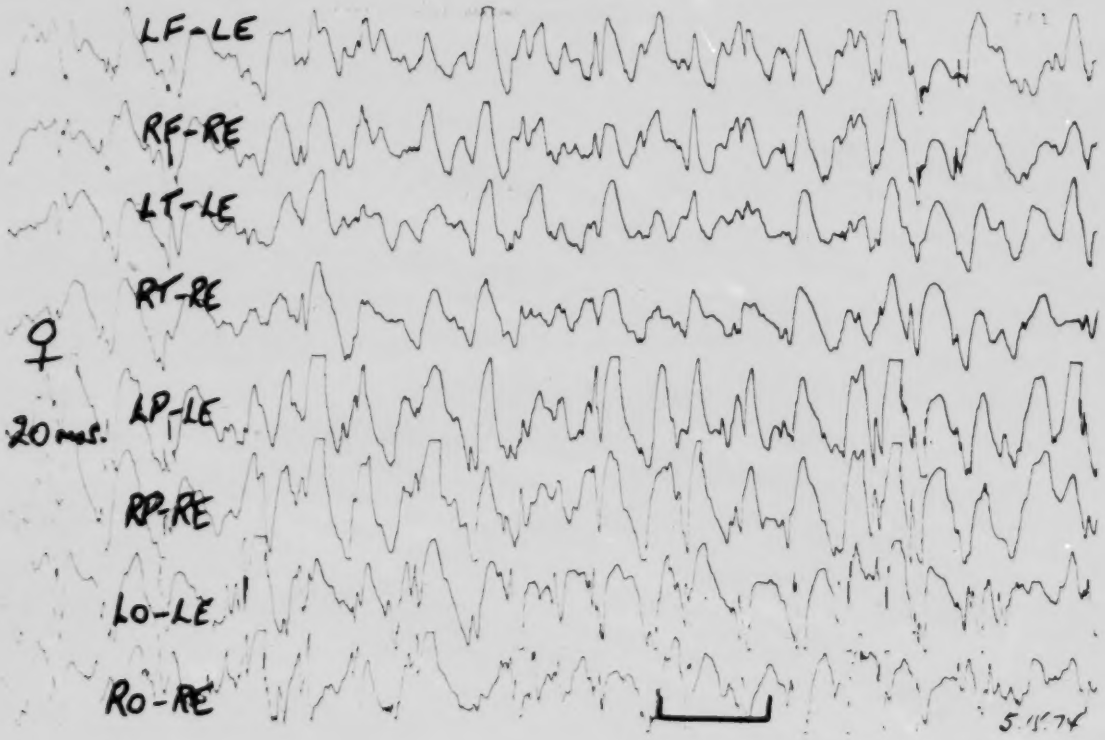
One of the most disturbing seizures that we deal with in pediatric neurology is the infantile spasm for which there are very few treatments available. We have to search for more effective control of the epilepsies caused by structural and degenerative cerebral lesions. Serum determinations of anti-convulsant drug levels have helped but clinical judgment and the need for new medications are more important in children.

Infantile spasms. Myoclonic spasms occur particularly in the first six months of life and almost entirely in the first year. The causes of these attacks are diverse; the etiology is undetermined in 43% and in the

remainder there is a history of birth injury, anoxia, pre-natal injury, post-natal head trauma, cerebral dysgenesis, encephalitis, or DPT immunization. Several authors have referred to the onset of infantile spasms after immunization procedures, and there does seem to be a relationship between pertussis immunization and sometimes polio immunization and the onset of hypsarythmia and infantile spasms.

Figure 1

EEG showing hypsarhythmic pattern
in a 20-month old infant with myoclonic spasms



There are very few cases of familial incidence of infantile spasms, but where the etiology is phenylketonuria, there is a one-in-four chance of subsequent children being affected.

Several years ago, a large number of children, on the East Coast particularly, were reported as having infantile spasms and other seizure patterns after receiving a formula deficient in Vitamin B_6. After the formula was changed the seizure disorder was controlled and there were no further convulsions.

Dr. Pampilioni from the Hospital for Sick Children in London reviewed his cases of infantile spasms and found that, when followed up to seven or ten years of age, 25% of the children had evidence of tuberous sclerosis, a congenital disorder affecting the brain and skin and many other organs of the body. It is a diagnosis frequently missed in infants with seizures, but it becomes evident at a later age when the child develops adenoma sebaceum on the face.

The most effective therapy in the treatment of infantile spasms is ACTH given intramuscularly; cortisone will effect control in some cases but is less effective. The mechanism of action of ACTH is unknown and much more research is needed in this area. Knowledge of the mechanism of action of anti-convulsants would speed up the discovery of the etiology of these seizures.

The earlier the treatment of infantile spasms is initiated, the better the response. In a study of ten patients less than one year of age, nine had a good response; of nine patients diagnosed or treated at one year of age or older, only two were improved.

Nitrazepam, or Mogadon, is used in Europe as a very effective sedative, and it was introduced in the U.S.A. on an investigational basis for the treatment of infantile spasms. It had a wonderful potential for control and successful therapy of these seizures, and the effective daily dose was significantly smaller than that of other anti-convulsants. Although a number of Hospital and Epilepsy centers in the United States demonstrated the efficacy of Mogadon there were too many problems with FDA requirements for its successful development by the manufacturer. Clonazapam, another related compound, seems somewhat less effective than Mogadon but its acceptance by the FDA is probable.

These benzodiazepine derivatives have much potential as anti-convulsants, the rapid onset of tolerance being the main limiting factor.

Petit mal. Petit mal is a pattern of seizure which seems very simple and benign but it is often difficult to control. In using various drugs in the treatment of petit mal, the degree of control varies, but so does the toxicity, and it is important to take this into consideration when deciding on the treatment of choice. For example, in comparing Diamox and Zarontin, the percentage control is about equal, but toxicity associated with Diamox is about 10% compared to 24% with Zarontin. It is probably better to start treatment with the less toxic drug and proceed to the alternative if the seizures are not controlled.

Febrile convulsions. The febrile seizure is a problem attended by much controversy, particularly in regard to therapy. The age of onset is usually between six months and three years; few children have attacks under six months of age and the condition is rare after five years. One

in fifty children under five years of age will have one or more febrile seizures, and about 10% of children under seven years of age who come to the hospital because of some febrile episode will have a febrile seizure associated with this. These seizures will recur in 50% of cases, about 10 or 12% having more than four seizures. One-half million children in the United States are affected by febrile convulsions.

The importance of the febrile seizure is that some of these patients go on to have epilepsy or spontaneous seizures; the incidence of this occurrence has varied according to the selection of cases with or without complications. The late Dr. Peterman included many patients with brain damage and found that 40% had spontaneous seizures; Dr. Lennox, in a restrospective study, found an incidence of 77%; Dr. Livingston, who selected patients arbitrarily, excluding those with a family history of epilepsy, with prolonged seizures, focal seizures, and brain damage, found that only 3% went on to have spontaneous, non-febrile attacks. In our own unselected group, we found that 21% had at least one spontaneous seizure, and of these, 5% had recurrent seizures which could be categorized as epilepsy. We found that the duration of the febrile seizure was a reliable prognostic factor in determining the occurrence of spontaneous seizures later and the need for anti-convulsant medication on a regular basis. In the children who had a febrile seizure lasting less than five minutes, only a small percentage would have non-febrile seizures; whereas about half of those with seizures lasting longer than twenty minutes went on to have spontaneous seizures. We also found the EEG to be important. If it was abnormal and showed seizure activity, then the chances of spontaneous seizures were about 60%.

There is some controversy about the benign or serious nature of these attacks. In some cases, Status epilepticus has been allowed to continue with fever and afterwards the child has severe brain damage; however, the incidence of severe brain damage is small in comparison with the number of febrile seizures occurring under five or ten years of age.

Since our study in 1958, three studies have been reported indicating that if phenobarbital is given regularly and daily, after the first febrile seizure, and if this treatment is monitored by doing repeated serum determinations of the drug, subsequent febrile seizures can be controlled and prevented. Dr. Margaret Lennox presented some data to this effect at a conference near London last year but at the end of her report she expressed doubt whether this method of treatment should in fact be given; phenobarbital has been found to produce hyperactivity or to exacerbate hyperactive behavior in children, to make children irritable, cause sleeplessness, and possibly to have some deleterious effect on their ability to learn. We, therefore, must use judgment in determining whether a child with one short febrile seizure should be put on phenobarbital from the age of six months to five years continuously as is advised by some neurologists.

We need more research before we can answer some of these questions and solve these problems. The Epilepsy Foundation of America has provided funds for research in epilepsy but they are limited. Last year there was a study which came before the Research Committee comparing the learning ability of two groups of children, one that received phenobarbital

regularly and one where it was given by the intermittent method at the time of febrile episodes. This important study could not be funded because of fund shortages. One of eighty applications the Committee reviewed, only five or six could be funded. There is an urgent need for research support.

DISCUSSION

Dr. Gibbs: We have been separating, really re-defining, the febrile convulsion, and this has led to some interesting conclusions. If we define febrile epilepsy as convulsions with fever, followed by a normal EEG, we find there is a very high familial incidence and extremely low incidence of seizures later in life; the prognosis is excellent. If, on the other hand, we take those seizures which occur with fever and call them, instead of febrile convulsions, convulsions with fever, and find an abnormal EEG after the initial episode, then the prognosis is not as good and perhaps the need for anti-epilepsy therapy is much greater.

Dr. Millichap: Dr. Gibbs is repeating the work and reports published many years ago by Dr. Livingston in Baltimore. If we are to arrive at a better scientific understanding of the febrile seizure and its significance, I am not sure one can make an arbitrary selection of cases in this way. At the conference in England, I was surprised to find that some doctors were also including patients with meningitis and encephalitis within this definition of febrile seizure because they felt it was not possible to make any differentiation other than a seizure associated with fever.

Dr. Gibbs: Perhaps a way of explaining the kind of findings we see would be to say that by excluding those cases that have convulsions with fever from the febrile convulsion group when there is an abnormal EEG, we are really excluding all those cases where there is even subtle evidence of meningitis or encephalitis. I think the EEG is perhaps picking up some cases where we can't find spinal fluid signs, et cetera, to confirm the meningitis or encephalitis. It is a very difficult diagnosis to make in many of these cases, yet it is felt by some that these children are suffering encephalitic episodes.

Dr. Millichap: Without the occurrence of an exanthema, persisting coma, delirium, neurological abnormalities or pleocytosis in the spinal fluid, the diagnosis of encephalitis with a febrile seizure is indeed difficult. Unfortunately, the EEG findings are not sufficiently specific to confirm a causative diagnosis.

Opening Remarks

Don A. Olson, Ph.D.
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Chicago, Illinois

We have a long list of very distinguished people here today, and it gives me real pleasure to introduce the Chairman for the afternoon session, Dr. Benjamin Boshes. Of all my involvements at Northwestern, one that gives me great pleasure is to be a member of his department. I have been a member for the past several years, and we have been able to work on a number of programs together here at the Rehabilitation Institute.

Dr. Boshes is Professor and Chairman of the Department of Neurology at Northwestern University Medical School, and formerly Chairman of Psychiatry and Neurology when the departments were combined. He is on numerous committees and one of them is the Medical Advisory Committee to the Epilepsy Foundation of America; he has been on this committee for many years.

Dr. Boshes will chair the session for the afternoon, and I hope he will have a chance to give us the benefit of some of his comments.

Chairman B. Boshes:

I am very pleased to be here. I am very active in rehabilitation in epilepsy and serve as the liaison person with government agencies, constantly reviewing federal legislation, and requests for grants in the various agencies that deal with these programs. Therefore, I was very pleased when Dr. Olson asked me to participate in a session as one of the chairmen.

Treatment Needs of the Epileptic: The Adult

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Much has been written on the subject of epilepsy and convulsive disorders. It is well to recognize epilepsy not as a disease, per se, but as a symptom, therefore the use of the term "epilepsies." It may be present alone or in association with other diseases.

The modern era of clinical epilepsy was really introduced by Hughling Jackson as far back as 1870. He described epilepsy as "a sudden, excessive and rapid discharge of gray matter from some part of the brain." He did not have an electroencephalograph but it sounds as though he did. The different forms of epilepsy were due to variations in the site of the "discharging lesion." "It is certain that there are varieties of epileptic seizures, each marked by a particular place of onset of the convulsion." Thus, from these statements it can be seen that Hughling Jackson felt that seizures were all symptomatic.

In 1888, in discussing the essential meaning, he said, "I urge strongly that the great thing as to the diagnosis of epilepsy is not the quantity of the symptoms nor the severity of the fits, but the paroxysmal nature... Again, loss of consciousness is not essential for the diagnosis. There may be defective consciousness only." In other words, alterations or clouding of consciousness is a part of seizures, but it is necessary to elicit this by diagnostic study and adequate history, usually from the family or observation.

Many times what the patient is unable to tell one is more diagnostic than what he does relate. This makes establishing the diagnosis the most important part before starting any formal treatment. A good history, from the family, the patient, and any individual who may have witnessed the attack, is necessary.

Next are the medical investigations, that is, physical and neurological examinations, X-rays of the skull, electroencephalography, and if necessary, other types of neurodiagnostic measures, such as spinal fluid, brain scan, with or without pneumoencephalography, and arteriography. The EEG may be normal in a percentage of cases, even in the presence of severe epilepsy. Where there is a question of tumor, then the other methods I have mentioned should be used. In some patients, a more detailed social history may be important as well as psychological testing. It would be advantageous if we did this routinely on every patient, but not economical.

I will not spend much time on descriptions of the classical seizures which may be generalized, like grand mal, petit mal, focal or psychomotor seizures which look like a generalized seizure. From personal experience, it seems that there is a great reticence on the part of medical students, doctors, lay people, and society, to consider the symptom of seizure in the correct light. Even in the face of characteristic signs, they may

prefer to reach the conclusion that there may be heart disease, hysteria, and other conditions before an epilepsy is considered, yet this should be the first that should be considered.

I am sure you know the characteristic signs of seizure, that is, aura, tonic, clonic movements, injury and incontinence which may or may not occur. As I mentioned, the only thing elicited may be that there is an alteration in consciousness with a paroxysmal disorder or symptom which is repetitive. In petit mal sometimes we miss the diagnosis because the patient and parents may not be aware of it. Teachers may be more aware that there is something occurring in the child in that he is staring and not always paying attention. He may not have other signs in addition to the brief periods of unconsciousness.

In psychomotor seizures, which include temporal lobe seizures, diagnosis is sometimes more difficult and sometimes takes longer study, especially where there is bizarre behavior, repeated temper tantrums, clouded states, and occasionally psychotic behavior.

Once the diagnosis is established of any of these symptoms the next question is, what do you do about rehabilitating the patient? In dealing with epilepsy, one should remember that this is a chronic condition. In all chronic conditions, it is important to tell the patient and the family that treatment is necessary over a long period of time. A frustrating fact in chronic conditions, such as diabetes, allergy or heart disease, is that often the patient and family go from doctor to doctor, clinic to clinic, repeating diagnostic procedures and running up bills but not following through on treatment. What they are looking for is a one-shot cure or someone to say there is nothing wrong with the patient. This is a common symptom of denial.

The next thing to do is simple drug therapy. When I was younger, I thought that all we had to do was make a diagnosis, give medicine, forget the personality and everything else, and we would get good results. I have learned bitterly that this is not the whole story.

However, in a review of patients in Northwestern University Epilepsy Clinic and from my own practice, we find that if we treat the simple seizure without any problems by giving the right drug, we may give a remission of 50-60% of all seizures. It is no longer necessary to intoxicate patients to produce a remission of seizures. We now know, with new drug methods and blood level measurements, that we not only talk in terms of grains of medication, but in drug levels.

Where there is a problem in seizure control or intoxication the measurement of blood drug level is important. The first blood level we had was in bromides in the thirties.

In follow-up we find that in 50-60% of the patients there is no trouble after making the diagnosis and putting them on one medication. They are ready to get on with their business of work, school, and all degress of social contact. Another 20% will require more than one drug to accomplish the remission, and in the last 20%, remission is more difficult to obtain. In these more recalcitrant patients major seizures are

usually complicated by other ones, that is, psychomotor seizures.

In the future, perhaps after further investigation, we will have more drugs, better methods of treatment and we will be able to help the last 20%. Our goal is to find out what more is wrong with these patients. By the various diagnostic methods we have, pneumoencephalography, arteriography, brain scan, and even exploratory surgery, we try to find a focus in the brain. By means of stereotaxic exploration, if a focus of discharge is found, we can help these patients.

If we accomplish stopping of seizures or producing a remission, the child should be able to attend any ordinary school. As neurologic consultant to the Chicago Board of Education I can say that we do not segregate patients with epilepsy. They go to a regular school. They should be allowed to participate in any athletic pursuits of a non-hazardous nature.

From the standpoint of an adult's occupation, he may engage in any type of non-hazardous occupation, and there is enough literature to show that industry has few troubles with them, provided they are controlled and in a non-hazardous situation. We do have to worry about compensation and insurance laws as a deterrent to employment.

These patients should be able to drive a car if they are seizure free for at least a year. Most of the states provide this. They also provide that patients should be taking medication and be under the care of a competent physician.

As a part of the Committee on Epilepsy and the Law, there are some states that will not let a patient marry but most states now have changed this. There is no reason for a patient not to marry and bear children, provided the disability is not frequent or the seizure disabling. As far as heredity is concerned, the actual clinical evidence shows it is no greater than in diabetes, hypertension or obesity.

General diet is of utmost importance. Fatigue and long periods without food may precipitate seizures. Alcohol is always a problem. Patients with epilepsy should not drink. The main problems are with alcoholics, not the patient who has an occasional drink. We have to decide whether a patient is an alcoholic or just an epileptic whose seizure is precipitated by an occasional drink. In most patients, the alcohol is the main problem and disability, not the epilepsy.

When we are not solving the seizure problem, what are the things we have to look for? In groups of patients, if the seizure is the only problem in rehabilitation, there are very few problems getting them back to social, intellectual, or psychological remission. However, there are patients who have a psychological reaction to the seizure; it may cause a reaction of emotional, social problems, and then cause vocational problems. If the epileptologist is not prepared, then there is a problem and additional help is needed in treatment.

I feel that any person who handles epilepsy should be able to deal with all the problems with ancillary help. Some social or psychological testing may be needed; the seizure may be a psychological problem in itself. There may be bizarre behavior, confusion, post-seizure mood

disturbances, agitated states, psychotic states, even occasional rage as a result, usually when the patient is restrained.

Actual assaultive behavior is rare, in spite of recent unpleasant publicity. My experience is that the only time the patient has had any trouble with rage and assault is when he is restrained, by his family, a well-meaning person on the street, or a police office. Sometimes these patients are arrested for combatting an officer; the police have to be made more aware of this possibility.

In an interesting study by Knox, 7% of 494 patients suggested episodes of assault. There was no aggressive behavior in 84%. In 14%, resistance to attempts at restraint was noted. One patient behaved in a potentially homicidal fashion. In 1% the attack lasted five minutes or less; in 12% it lasted five to fifteen minutes, but none over one hour. So actually there was not enough time for them to prepare any kind of assault. In 93% there was total amnesia for the attack, which makes a good diagnostic clue. In the remainder, less than 1% had partial recollection.

It is certainly difficult to distinguish between true and fraudulent amnesia. It can be seen that the defense of amnesia for aggressive, assaultive or homicidal behavior is rare, and certainly should not be predicated solely on electroencephalogram but by a good clinical evaluation.

Occasionally there are psychological problems due to the communications media, for instance, in the Ruby case. Where a murder is committed and there is a little abnormality on the EEG, the defense tries to diagnose an epileptic. This is usually not so, and it causes a great deal of furore in patients who have had seizures, and the problem comes up often both medically and legally.

A problem may occur in the borderline cases where many of these patients simulate hysteria but have enough other epileptic features to make them problems in diagnosis and subsequent treatment. Most of them have psychomotor seizures with bizarre features requiring prolonged observation.

In 1935, when I did a study in our clinic, we had three out of 100 patients diagnosed as hysteria. The older attending men who were all experienced neurologists had to attest to the fact that they thought these were hysteria. I went on to being an attending man at Cook County, and these three patients came in later in status epilepticus.

A person with seizures has a personality, and sometimes the personality is more important than the seizures. We may control the seizures but then we are left with a person with emotional problems who needs definite psychotherapy. A thirty-year old school teacher, who was a well controlled patient, recently married. He became depressed and had seizures. I found out that his wife was a dependent, immature, neurotic woman, complicated by an intolerable mother-in-law. He did not solve the problem until he divorced his wife; he is doing well now.

If we follow patients for a long period of time, we may find they

develop organic changes in which the seizures now become a problem. It is necessary to do other tests to make sure the patient does not have a tumor or some other type of brain disease that may be more important than the seizure phenomenon.

In school children seizures associated with mental deficiency may present a problem. These patients are disabled mainly because of the intellectual disorder. In such cases we need family help to supervise the medication and have the children acquire whatever schooling is possible.

Rarely is status epilepticus a problem. I will not go into the treatment except to say that these are emergency situations requiring hospitalization and intensive treatment with barbiturate and/or valium, then a loading with an anti-convulsant to save the person's life as well as produce a remission. However, we rarely see the minor seizure or petit mal status in which the patient is in a coma or stupor. In order to diagnose the status it is sometimes necessary to monitor the patient at the bedside with an EEG. Then the diagnosis becomes evident, and with intensive medication the patient comes out of his stupor.

One of the big problems, not only in children but adults, is the family reaction to the patient's illness. Nobody wants any type of illness and certainly nobody wants epilepsy. A recent patient who complained about his family and his doctor never talking to him was hospitalized for seizures. He did well with medication, went home, and his family immediately took his medication away because they did not like the diagnosis. The only treatment there is a new environment, which is easy to prescribe but not easy to carry out.

Now, iatrogenic results of treating problems include drug reactions These are potent drugs and they require supervision. One must have knowledge of what these drugs can do. Fortunately, now we have more methods to determine blood levels by means of Liquid Gas Chromatography. We are more familiar with acute reactions of Dilantin. But I have seen patients on Dilantin for many years suddenly develop cerebellar signs or peripheral neuritis. So one has to be on the alert that the drugs being used may cause problems. One should be clinically aware of this and use blood levels to see if they are becoming intoxicated.

The blood levels do one other thing which is even more important. When we did blood bromide determinations in the thirties, it surprised me with my intensive supervision that 40% were found not to be taking any medication. This is no surprise now, because with the new methods some groups have noticed that 50% of patients are not taking their medication. This is obviously a problem.

There are still social problems. The patient has a problem in school, at work, and with his social contacts. This is one of the biggest problems, which is better now but still not solved. A great deal of education is needed. One of the major problems is lack of money for research. One of the difficulties of raising funds is getting volunteers who want to be identified with epilepsy. This was brought out in recent Washington hearings.

We are quite aware of withdrawal seizures from drugs. These do occur with anti-convulsant drugs. The patient is doing well and suddenly is having seizures. The first thing we think of is that the patient stopped his medication. This often happens in the hospital with alcohol. A patient who is drinking may come into the hospital for a herniotomy, and ten days later he has convulsions. This similarly does occur with stopping of anti-convulsant medications, and we must be aware of it.

Denial of illness occurs with the patient, and with the family, with many psychological as well as physical problems. As I mentioned before, these patients go from doctor to doctor, and from clinic to clinic. Even in the Veterans Administration where they get their tests for nothing, they leave the clinic, stop all their medication, and go to another clinic. These people look for a miracle, which we do not have.

One of the problems is erroneous diagnosis of epilepsy. A patient may come to me for consultation from a doctor who has been treating the patient for an epilepsy. This happens in school children who have behavior problems and who have been labeled epileptic solely on the basis of an EEG. These patients need more clinical study. There is nothing wrong with a trial of anti-convulsant medication, but if they do not respond they should be investigated to find out what is wrong with them and treated appropriately. Diagnosis of epilepsy is a clinical one.

DISCUSSION

Dr. Millichap: On the reference to Ruby and the murder trial. You will remember that when Ruby died he was found to have a carconoma with metastases. The question arose in my mind as to whether that EEG abnormality could not have been a seizure pattern. There was so much disagreement among the experts at the time of the trial that I thought when the news came out that Ruby had these metastases in the brain, that might indeed be significant. I'm not saying that Ruby committed murder because he was an epileptic. I think this question comes up fairly frequently.

In my practice recently I was asked to run an EEG on a child. He had a spike wave, and he was treated by the pediatrician for seizures. Subsequently he committed murder. This was a premeditated murder where the child actually had a revolver in his pocket when he did it. So I don't subscribe to the idea that an epileptic is more likely to commit murder, but it does bring up this idea of the epileptic personality, and I would like to hear your current thoughts about this.

Dr. Arieff: First, I do not really subscribe to an epileptic personality per se. I think this comes from literature, especially from institutions. I think there are recent tests that show on the basis of personality evaluation that those with so-called epileptic personalities have some type of brain disease which may cause the seizures as well as personality

Dr. Arieff: (cont.) changes.

Second, I am not questioning that Ruby may have had metastases, but his murder was not due to epilepsy. His judgment may have been psychotic, and on that basis, it is another matter. It is the same with your patient. If he has brain disease, his judgment is not good and on that basis he may have an out. But I don't think we should label him epileptic and say the epilepsy caused him to commit murder.

Member: What percent of epileptics are candidates for neurosurgery, and of them, what percent recover without seizures or with them substantially reduced?

Dr. Arieff: In our experience here, probably less than 10 to 20% have neurosurgical lesions, and of those, the majority do well if they really have a focus that can be cut out. In our series we do not have that many, surprisingly. The ones we have selected on good criteria, clinically and on EEG, do well.

Medicine and Machines: Present Status, Future Needs

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I am pleased to have the opportunity to briefly review the technology related to the diagnosis and treatment of epilepsy for such an interesting and involved group. The subject is so broad that in order to cover even the main points I will have to generalize a great deal, but it must be remembered that medical technology does not operate on generalizations. Quality results and effective application depend on a chain of fine details.

Of prime importance to the understanding and treatment of an epilepsy is its classification and the identification of etiology. The electroencephalogram provides the means of classification and, because of an enormous body of experience, often provides strong leads regarding probable causes based on the classifications. The confirmation of potential causes of epilepsy includes everything from epidemiological sleuthing and sophisticated virology to the complex hardware and technology associated with computerized X-ray techniques, but it is electroencephalography that provides the key to the diagnosis of epilepsy. About fifty different electroencephalographic varieties of epilepsy have now been identified (Gibbs, F.A., and Gibbs, E.L., 1967), each with its own characteristic electroencephalographic appearance and pattern of etiologies, prognosis, symptomatology, and effective therapies, and the list continues to grow.

It is important to remember that an abnormal EEG does not necessarily mean that a patient will experience convulsions or any other type of spell. At least four or five of these classifications involve epilepsies which are associated with motor convulsions and it is also entirely possible to have EEG evidence of a convulsive form of epilepsy and yet never experience convulsions. The EEG only classifies an abnormality; the likelihood of one type of spell or another is then a matter of statistics based on clinical experience. Thus, we find ourselves on the prongs of a dilemma. In a legal sense, a person may not have epilepsy until he experiences convulsions or unconsciousness and medically, many physicians will not treat epilepsy until the patient experiences convulsions or unconsciousness. Yet electroencephalography makes it possible to detect the presence of epilepsies which are statistically likely to produce convulsions, even though the patient may not have experienced them up to the time of the EEG recording. Since some patients with latent forms of convulsive epilepsy never experience convulsions or perhaps experience them only very infrequently, the question of whether to treat the EEG disorder in the absence of clinical evidence of epilepsy will, no doubt, remain hotly disputed. Forms of epilepsy that are highly associated with convulsions can also produce non-convulsive symptomatology, such as headaches, dizziness, nausea, double vision, confusional episodes and personality disturbances, which can be severe to the point of being incapacitating; the non-convulsive forms of epilepsy generally produce combinations of such symptoms.

When present, these symptoms are often classified as epilepsy if the EEG is positive and if the symptoms respond to anti-epilepsy medications. Experience has demonstrated that a patient with a positive EEG and presenting with some of these symptoms is very likely to respond to anti-epilepsy medication, whereas patients with the same symptoms and a normal electroencephalogram are unlikely to benefit from anti-epilepsy medication.

Electroencephalography, therefore, is an extremely useful and powerful diagnostic tool; however, the details of its application can profoundly alter its clinical effectiveness. We use the common ear reference recording system, originally pioneered by Frederic A. Gibbs (Gibbs, F.A., and Gibbs, E.G., 1950, 1952, 1964). In this system, the electrodes are placed on the scalp over anatomically active areas of the brain with bilateral symmetry. The ear lobes are used as inactive references for the EEG amplifiers. The electrodes themselves are attached to the scalp with a sticky conductive paste, making the process painless. During a recording, which may last for an hour or more, and includes a period of drowsiness and sleep, the basic recording pattern of a ten-channel machine may be changed only three or four times unless an abnormality is detected which requires additional electrodes or special recording techniques to sharpen the focus. The basic procedure is designed to take the broadest possible sample in order not to miss abnormalities which may occur only several times during the entire period of the recording and also to provide a uniform recording technique which permits the systematic comparison of thousands upon thousands of recordings.

Other electroencephalographic techniques, which are also widely used and accepted, place less emphasis on the anatomical placement of the electrodes and do not stress sleep. The International 10-20 electrode placement system divides the scalp into a grid based on 10% and 20% distances between the bridge of the nose and the back of the head and the ears. This sytem does not include an anterior temporal lead, which is important since a very large proportion of adult epilepsies can be detected only in the anterior temporal regions with such a lead. Because of the tremendous effort that may be required to obtain sleep in many instances, most laboratories perform sleep recordings "only when necessary." In my opinion, this represents a paradoxical situation since the majority of abnormalities are seen only during sleep and the waking recordings would give no indication of what patterns would be detected during sleep.

I would like to show you a few slides of some typical EEG patterns recorded using the monopolar methodology. The first is a normal waking recording (Fig. 1). The upper two channels, which are recorded from the left and right frontal areas, show large slow waves associated with eye movement. The lower two channels, which are recorded from the left and right occipital regions, show alpha activity when the patient's eyes are closed; alpha activity is usually blocked when a patient's eyes are open or when the patient is concentrating on a difficult mental task.

The second slide shows a normal sleep recording (Fig. 2). The basic frequencies are slower than in the waking recording and the frontal and parietal channels show runs of 12-14 per second activity, which we call

sleep spindles. These are characteristic of light but sound sleep. Asynchrony, or the absence of spindle activity, would indicate brain damage.

The next three slides show three different types of abnormalities which have a similar electroencephalographic appearance. They should serve as examples of how important it is to record under systematic conditions and to have experience interpreting EEG's. The first slide shows the 3-4 per second spike and wave of the classical "absence" petit mal (Fig. 3). This is the abnormality that correlates with brief staring attacks, not usually preceded by any warning or followed by any post-ictal state. Patients with true petit mal epilepsy are likely to outgrow it before or during adolescence and impairment of intelligence does not correlate with the disorder. The epilepsy is coupled to carbon dioxide metabolism and can be precipitated by hyperventilation or low blood sugar. Hyperventilation will usually precipitate a burst of 3-4 per second petit mal discharges during an EEG recording if the patient has the disorder. Petit mal epilepsy usually responds to Zarontin and Celontin; Diamox, a carbonic anhydrase inhibitor, can also be helpful. Tridione and Paradione are older medications than Zarontin and Celontin, and though more toxic, have been effective. The second slide in this group shows the slow petit mal discharges which we call petit mal variant; others may call it the 2-3 per second spike and wave (Fig. 4). This is not true petit mal and, depending upon the particular recording technology, may be difficult to distinguish from true petit mal. Petit mal variant discharges are not precipitated with hyperventilation. The typical spells in cases of this sort are major motor spells, often preceded by a drop attack. Retardation is very likely to be present. The attacks associated with petit mal variant epilepsy do not respond to the medications effective against true petit mal epilepsy; Dilantin, phenobarbital and others with similar spectrums are generally more effective. The third slide is an example of what we call pseudo petit mal (Fig. 5). These three examples of petit mal type discharges are quite classical and fairly easy to distinguish when presented simultaneously; however, it should be stressed that the picture is not always so clear, even under ideal conditions; experience can be very important. Pseudo petit mal is generally a rather benign disorder occurring in children. It is usually associated with mild complaints such as dizziness and blackouts, although motor convulsions do occur in a small percentage of cases. It is almost always outgrown without residual problems. However, the pattern does appear to represent a transition disturbance which, at the present, is not fully understood. Some cases of pseudo petit mal progress to types of epilepsy which are highly associated with motor convulsions and there may even be some impairment of mental skills. The three entirely different disorders portrayed on these three slides can be confused by poor EEG technology. If such confusion were to occur, the results of the EEG would be less than rewarding.

There is a great need for more consistent terminology when discussing epilepsy. The term "petit mal" is frequently used interchangeably to describe the epilepsy associated with the 3-4 per second petit mal discharges and other types of epilepsy which produce small spells or small motor convulsions. This can be very confusing since these other forms of epilepsy would not be expected to respond well to the medications effective against the 3-4 per second spike and wave petit mal epilepsy.

The next slide shows an example of the most common type of epilepsy in children; we call it 14 and 6 per second positive spike epilepsy because of the 14 and 6 per second positive frequency components (Fig. 6). The fact that the frequencies may vary slightly has led other electroencaphalographers to call it simply positive spike epilepsy or 14 and 7 or 13 and 6 per second positive spike epilepsy. In any case, the EEG appearance is very characteristic and easily recognized by persons with only a few days' experience. This epilepsy has been surrounded by controversy for more than ten years. Part of the problem goes back to technology. 14 and 6 per second positive discharges are most likely to occur during drowsiness or on arousal. Although they are easily detected with monopolar recording they may be obliterated by cancellation effects occurring during bipolar recording. Thus, if the patient is not held in a state of drowsiness for a few minutes or a bipolar recording system is used, the 14 and 6 per second pattern may not be detected. Another reason for the controversy can be traced to the fact that this disorder is extremely common, occurring in about one out of fifteen children, and it is a non-convulsive form of epilepsy. However, children with this disorder in their EEG's and some of the symptoms already described for non-convulsive epilepsies are very likely to respond to anti-epilepsy medications, whereas children with the same symptoms, but without the abnormality in the EEG's, are not likely to respond to such medications. The complaints associated with positive spike epilepsy are basically those listed above for non-convulsive forms of epilepsy and when these complaints are so severe as to lead to psychiatric care or medical consultation, it is sad not to attempt a therapeutic trial with adequate anti-epilepsy medications.

As electroencephalography is essential to the complete diagnosis and classifications of epilepsy, anti-epilepsy drug blood level determinations are essential to the modern treatment of epilepsy (Gardner-Medwin, 1973; Rose, R.S., et. al., 1971).

Gibbs Laboratories, originally specializing in electroencephalography, has been involved with research and clinical services in the anti-epilepsy drug blood level field for about five years. At first, it seemed that blood level determinations would reduce the portion of uncontrolled epileptics to a small percentage in a very short time. Now, approximately ten thousand blood levels later, we have developed a more sophisticated opinion of the advantages of the determinations. With the problems of technology largely behind us and the ability to determine essentially all of the anti-epilepsy drugs (Fig. 7-8) accurately, quickly and inexpensively (Gibbs, E.L., 1974; Woodbury, D.M., 1972), we discover that only about one out of five patients referred to our laboratory benefits significantly from the blood level determinations he receives. Our experience has been echoed by many physicians and specialists and in some circles there are grave doubts as to whether blood levels have any advantage over clinical observation. Many physicians have heard that patients with very elevated blood levels were without side effects and yet were well controlled. There are unconfirmed reports of patients with negligibly low blood levels who take their medicine reliably and have spells when they miss doses. There is talk about plasma binding varying significantly from person to person, which might seem to indicate that standard ranges will never have useful meaning.

Why, then, are blood level specialists taking an ever stronger line on the importance and necessity of the determinations in the treatment of epilepsy? Why does our laboratory suggest routine determinations on all patients receiving anti-epilepsy drugs, even if they are completely controlled? Because, fundamentally, the blood level determinations must improve the treatment of epilepsy since they reduce the impact of such important variables as: differences in individual absorption and metabolism of anti-epilepsy medications; drug-drug interactions; patient inconsistency (medications); the effects of diseases and normally variable physiological states on drug blood concentrations; the inherently paroxysmal nature of epilepsy; hypersensitivites, et cetera. If there is confusion about this new tool and the majority of patients are not benefiting from its use, perhaps the difficulty lies to some degree with the methods of application. As with any new tool, the blood level determinations do not, in and of themselves, ensure an effective end result. In order for the determinations to meet their full potential, they must be employed within the framework of a systematic approach to the treatment of epilepsy, which includes an appreciation of the pharmacology and physiology (including electroencephalography) involved as well as human nature.

Probably the single greatest obstacle to the treatment of epilepsy and understanding and application of drug blood levels is that patients frequently do not take their medications consistently. In fact, our experience has shown that about 50% of all out-patients with uncontrolled epilepsy do not take their medications consistently and in the overwhelming majority of such cases, physicians believed that the patients were reliable. This percentage is almost the same whether we select from educated, affluent populations or lower income, educationally handicapped populations. In-patients receive their medications more consistently, but experience has shown that even within a hospital setting consistency cannot be assumed. Irregular pill taking leads to great confusion over the meaning of drug blood level measurements. For instance, if a patient is not reporting seizures or side effects, variable blood level results may lead to the conclusion that blood levels are not a reliable indicator of the effectiveness of a given dosage. Actually, the patient may have outgrown his disorder, may be concerned about his driver's license, or may be just lucky. On the other hand, a patient might have optimal blood concentrations separated by a month or more and report seizures during the interim. A physician might reasonably conclude that the patient's dosages were inadequate despite the measured blood concentrations and increase dosages or place the patient on additional medications. If the patient had become careless about his medications before having the seizures, these steps might lead to even more inconsistent pill taking.

A major reason why patients do not take their medications consistently may be that they experience subtle side effects such as decreased short-term memory or sleepiness, even at blood concentrations that may be necessary for good seizure control and at which more obvious neurological side effects are rare (Gibbs, E.L., 1974b). Since most patients are not aware that many anti-epilepsy medications are very slowly absorbed and weeks may be required to achieve plateau blood concentrations, they decide to reduce or discontinue their medications except when they feel a spell may be coming on and then they may "take a little extra for luck."

Patients usually do not tell their physicians because that would be admitting to self-medication, which is frowned upon by most physicians. If a physician is not sensitive to this problem or discounts the significance of subtle side effects, which he may not see, relative to the threat of seizures, he may increase dosages or add additional medication only to have his patient reach a new level of non-compliance. Many patients do not take their medication consistently because they are simply forgetful or because their dosage schedules are complex and easily confused; others may have psychological reasons for not taking medications. Often the solutions require a great deal of skill, understanding, and, frequently, social services and psychological assistance; however, the routine use of reliable blood level determinations helps to pinpoint the problem and gaining a patient's trust helps to solve it. Patients are often reassured and more open if they are told that every patient is a miniature experiment, because of the differences that make him an individual, and that nobody can know exactly how to treat him without tests, perhaps some minor mistakes, and his candid cooperation. The patient might be encouraged to report possible side effects, though carefully discouraged from being overly sensitive. He should be advised of the rate of absorption of his drugs and what he can do if he misses a dosage accidentally.

Failure to understand the pharmacology and pharmacodynamics of the anti-epilepsy drugs or the effects of drug-drug interactions is probably the second greatest contributing factor to the misapplication of and loss of faith in anti-epilepsy drug blood level determinations. Most physicians are aware that Mysoline (primidone) is converted to phenobarbital and phenyl-ethyl-malonamide *in vivo*, but many do not know that a large number of anti-epilepsy drugs are converted to active metabolites; for example, Mesantoin (mephenytoin) is converted to Nirvanol (ethotoin), a drug which was withdrawn from the market some years ago. Before our laboratory began explaining results, we received numerous complaints of reporting significant levels of drugs that patients were not taking and of reporting negligible levels of the drugs they were taking. A more subtle and potentially serious problem occurs when a patient is intoxicated on an anti-epilepsy drug, perhaps phenobarbital, as the result of combining Mysoline and Mebaral therapy or as the result of unexpectedly slow drug metabolism or excretion. If it is not understood that an elevated blood level can result in a relative reduction of seizure control and that too rapid a reduction of the blood concentrations can result in an important increase in seizure frequency as well as shock and status in more extreme cases (Gibbs, E.L., 1974c), reporting an elevated level without explanation can lead to serious complications for the patient and a backlash against the blood level determinations. Occasionally medications are reinstated or even increased following a poor response to an initial abrupt reduction of dosages. It appears that dosages may be reduced prior to requesting blood level determinations in some cases of suspected intoxications. Because of the value of blood level data in managing an intoxication, especially when multiple drugs are involved, this course of action is not recommended.

Another misunderstanding related to the complex pharmacology of the anti-epilepsy drugs occurs when a patient is found to have some neurological side effects and a slightly elevated drug blood level but his seizures are controlled. Perhaps he is taking 300 mg. of a drug per day

and his level is elevated above the optimal range by 1.5 times. If it is not realized that the elimination of some drugs follows second order kinetics, the patient's dosage may be reduced to 200 mg. per day (Fig. 9). This reduction might result in a blood level below the optimal range and the patient might go out of control before a second determination is performed. Frequently, the end result is that the patient is placed back on the 300 mg. dosage and it is concluded that the side effects are a necessary trade-off for control. The reverse of this situation occurs when a patient begins with a low blood concentration and his dosage is increased by more than it should be. The concept that a 20-30 percent change of dosage can, depending on the drug, cause a blood concentration change of two times or more when the patient's blood concentrations are near optimal levels is sometimes hard to convey, especially since anti-epilepsy medications have been prescribed without the aid of blood level measurements for more than thirty years.

It is also important to understand something about the half life of the various anti-epilepsy drugs when interpreting blood level data. Because phenobarbital has often been prescribed as a sedative or acutely for prophylaxis during febrile episodes when there is a history of simple febrile convulsions, many tend to think of it as rapidly absorbed and relatively short acting. Actually its half life is measured in days and about three weeks is required before a relatively stable plateau level develops in most individuals placed on a maintenance dosage (Fig. 10). As a rule of thumb, it is necessary to wait approximately two weeks from the time an anti-epilepsy medication is started before expecting blood concentrations approximating plateau levels. Important exceptions are the benzodiazepines, which plateau in a matter of days, and the oxazolidinediones, which may not plateau for a month or more.

Drug-drug interactions can also lead to some very perplexing problems if they are not considered. Many of the anti-epilepsy drugs interact metabolically with one another and more and more of other classes of drugs are being found to interact also. The fact that isoniazid blocks the metabolism of diphenylhydantoin is rather well known, but the potential effect of less dramatic medications such as birth control medications or chronically employed laxatives or antacids is often overlooked.

Normal changes of metabolism, such as those associated with pregnancy, can also lead to changes in drug requirements (Gibbs, E.L., 1974d). As a woman's pregnancy progresses, her requirements for anti-epilepsy medication usually increase up to delivery by which time they may have doubled. Following delivery, they may fall back to pre-pregnancy levels in a matter of weeks.

Two changes in the basic approach to anti-epilepsy drug blood level determinations would greatly improve their general usefulness and accelerate research and development. First, it would seem important to repeat blood levels at two-week intervals until a patient is controlled and his blood levels have been stabilized at the desired levels (Fig. 11). Following the initial intensive phase of medication selection and dosage adjustment, routine blood levels performed three times a year in conjunction with CBC tests would be helpful. If at any time a patient develops side effects or has a breakthrough in seizures, levels should be obtained

in a matter of days. This plan is suggested for controlled patients also, in order to provide a baseline upon which to judge any problems that may develop in the future; however, it is essential that the cost of determinations be kept as low as possible without loss of quality or necessary repeat determinations will not be obtained.

Second, laboratories performing the blood level determinations should be encouraged to take an active role in research and in the reporting of results. The early problems at Gibbs Laboratories led us to require that all samples be accompanied by a completed history sheet (Fig. 12). This serves three very important functions: (1) it provides enough redundancy of information so that laboratory and health care delivery errors can be kept to extremely low levels; (2) it humanizes the laboratory samples and thereby makes it possible to maintain a staff of skilled and dedicated technicians; and (3) it permits a steep learning curve and a scale of clinical research not possible any other way. The rapidly evolving knowledge of the anti-epilepsy medications is made available on a one-to-one basis through consultation reports and on a broader basis through publications. Physicians or groups interested in researching a particular aspect of anti-epilepsy medications are invited to tap this enormous flux of data. Laboratories performing the anti-epilepsy drug blood level determinations should also, if possible, complement their staffs with specialists interested in research and who have a working knowledge of neurology and electroencephalography. Initially our history sheets and consultation reports were greeted critically; however, as time passed the system became accepted as an excellent means of sharing important information in a rapidly evolving field. The reports have been especially helpful in that they encourage a dialogue between the referring physician and the laboratory which improves the quality of the data base developed in the laboratory and thereby improves the quality of information available to the practicing physician. We hope that this procedure will permit us to report in a few more years that blood level determinations are of benefit to essentially all patients.

DISCUSSION

Chairman B. Boshes: This is a very important subject and we should give it a few moments for questions.

Member: You mentioned that in one type of epilepsy the teenager would usually outgrow this particular type of seizure. Is there any possibility he would outgrow it without medication?

Dr. Gibbs: Yes, in fact, there is only the weakest of evidence that the anti-epilepsy medications have any curing effect. There is some evidence that controlling seizures will prevent some seizures and improve the likelihood that the patient will outgrow the disorder, but it is not a very strong or easily demonstrable fact. This assumes that the patient is not having serious seizures which could reduce the likelihood of his recovery by causing progressive injuries.

Member: You mentioned that each individual is different and will need different types and degrees of medications. I have heard it expressed that one of the problems is the cost of medication. Could you relate what the change of cost would be for medication?

Dr. Gibbs: Were you thinking in terms of whether the blood level determinations would increase or decrease the cost of medications?

Member: No, I'm thinking that different groups in our state have expressed that one of the primary problems is the cost of the medication, and I was wondering if there is any way you could equate what the cost could be?

Dr. Gibbs: The blood level determinations can only simplify a patient's medication. You may find that a person needs more or one medicine to get an effective level, then once he has reached an effective level, he may be able to discontinue two or three other medications. In that way, it may reduce the cost, but on the whole the blood level measurements do not reduce the cost of therapy very much. However, they dramatically improve the effectiveness of therapy, and insofar as seizures are a big cost to the patient, I would say the total impact is to reduce the cost.

There are certainly many cases in the hospitals where patients have not had seizures for many years, and when blood levels are run, the levels are found to be insignificant. In these cases there is a strong argument for discontinuing the medication if the EEG is normal, and that has saved a number of state systems a considerable amount of money.

Chairman B. Boshes: In most cases where either Dilantin or phenobarbital is used, the cost of medication is nominal. Medications that do cost are the unusual substances like Valium and Tegretol. Here the drug houses are trying to recoup the extensive research. But cost is becoming less and less a factor in the long run.

As Dr. Gibbs has pointed out, a medium of control has been achieved. An old method was to give the patient in status epilepticus intramuscular dilantin sodium. All that happened was that the Dilantin became encapsulated in the muscle but none was absorbed into the bloodstream. So we have learned a great deal through Gas-Liquid Chromatography.

Member: Is Gas-Liquid Chromatography a rather exotic procedure or do most hospitals have it available to them?

Dr. Gibbs: Most hospitals have the equipment but the difficulties arise in maintaining it, because the columns and certain instrument specializations that need to be set up to make the analyses work cannot be changed easily. One runs into

Dr. Gibbs: (cont.) trouble if one constantly switches back and forth from anti-epilepsy drug determinations to, for example, hormone determinations. The key to accuracy is having adequate internal standards and adequate controls running each day. On the whole, hospital laboratories, unless they are doing a great many of these determinations, do not have the time, money, or personnel to ensure that.

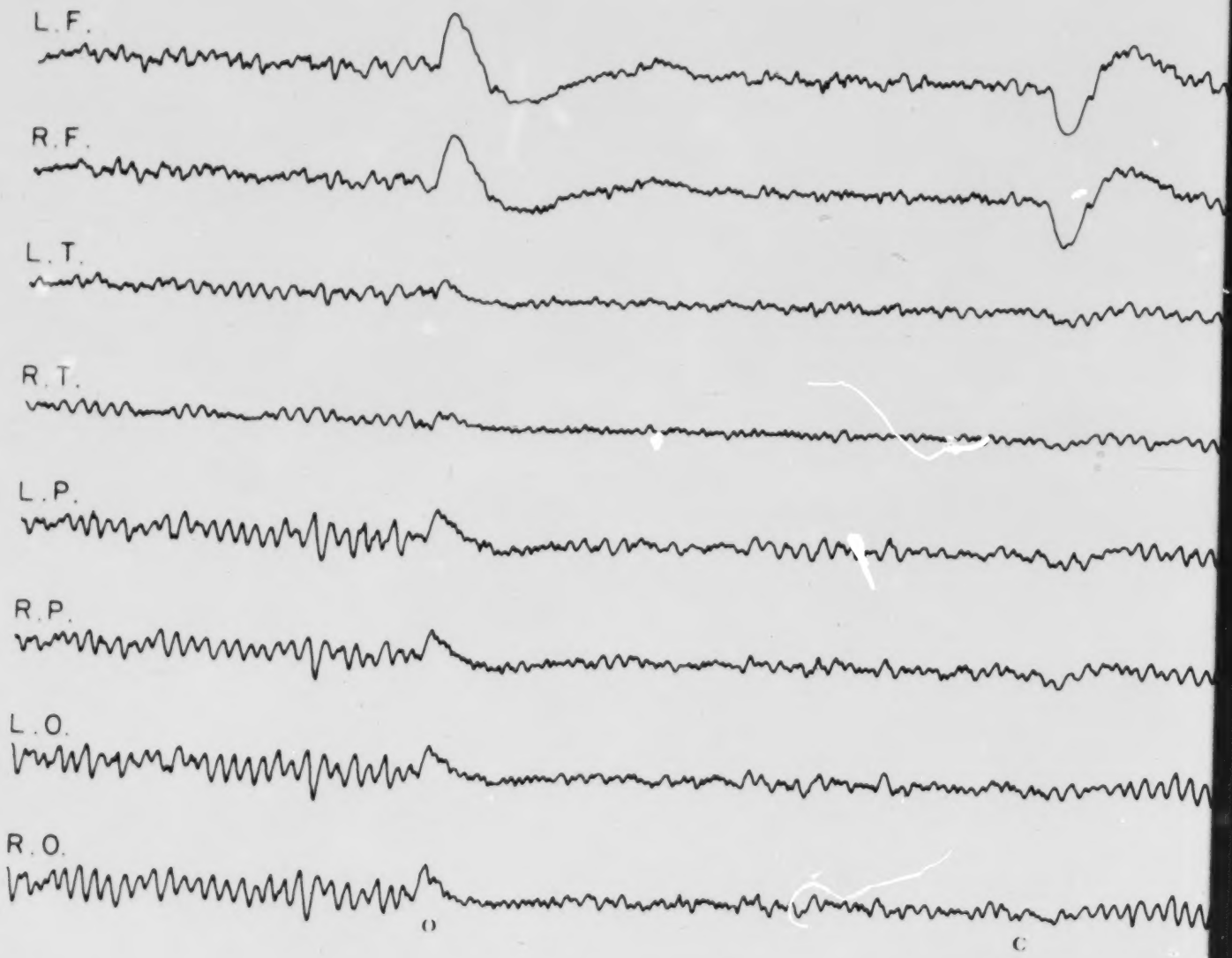
Chairman B. Boshes: The Epilepsy Foundation has two machines, one on the west coast, and one in Columbia. Now the machines will be moved to other places because each of these institutions has a machine of its own; they are being introduced around the country.

Member: I live in a city of less than five hundred thousand and there are five machines, but only one set up specifically to test for epilepsy drugs.

Dr. Gibbs: One should be adequate for a city of that size. The problem is lack of accuracy in many cases. I would suggest that any physician using these determinations should be on guard if he wants to use them effectively.

Chairman B. Boshes: In a community with three hundred thousand people, there may be between four and five thousand patients with epilepsy.

Dr. Gibbs: A laboratory with one Gas-Liquid Chromatography unit going fourteen to fifteen hours a day should be able to turn out thirty determinations in that time.



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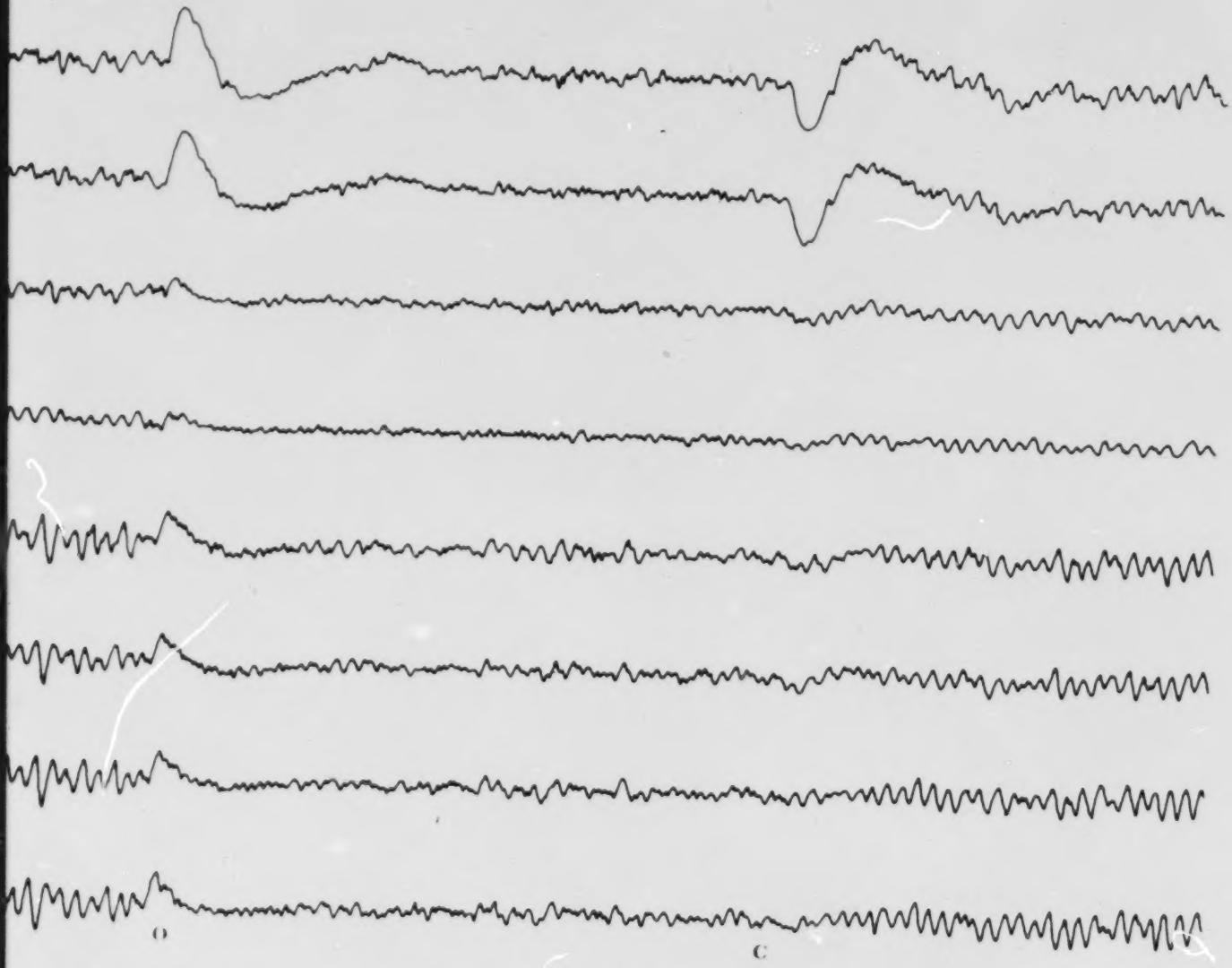
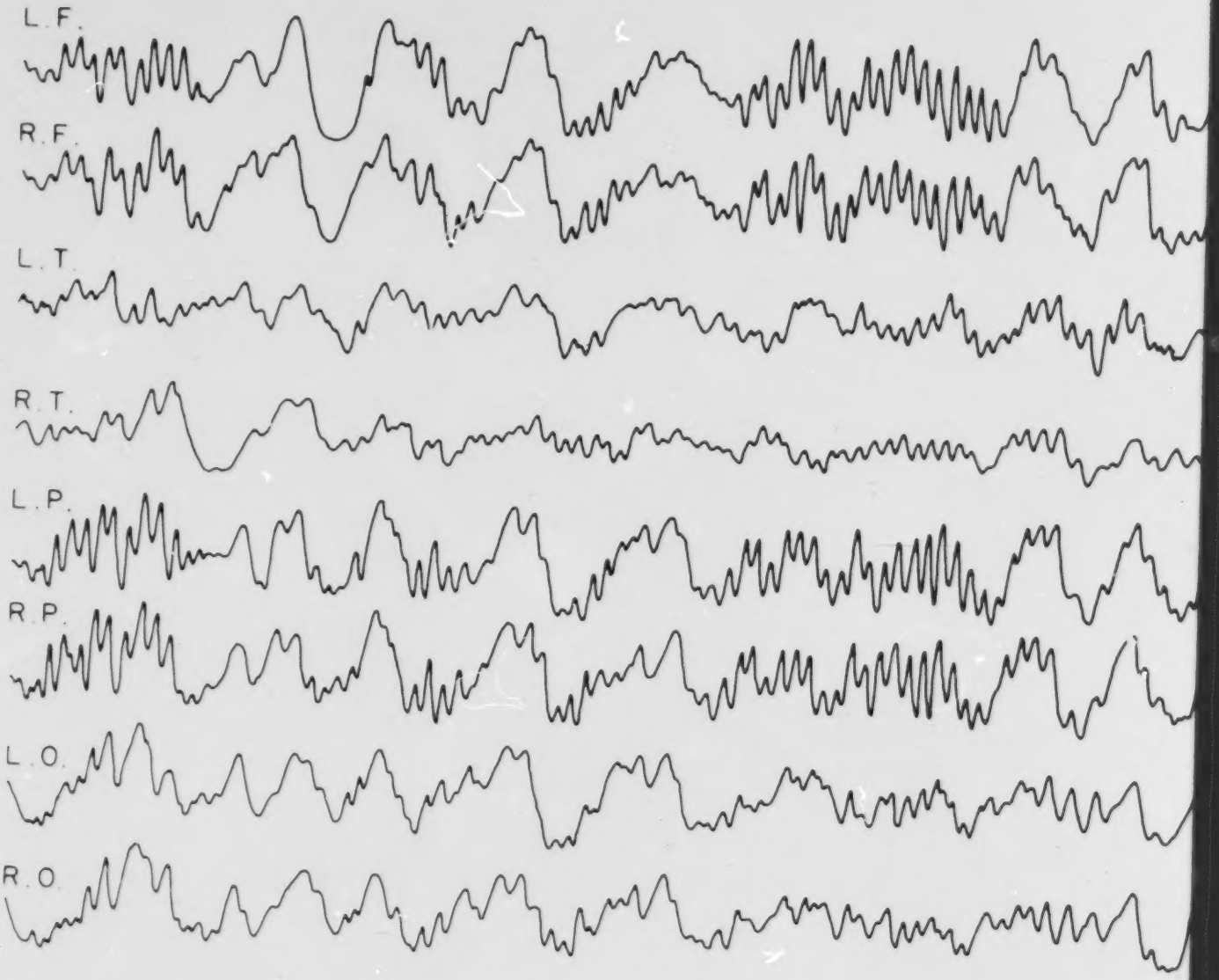


Fig. 1



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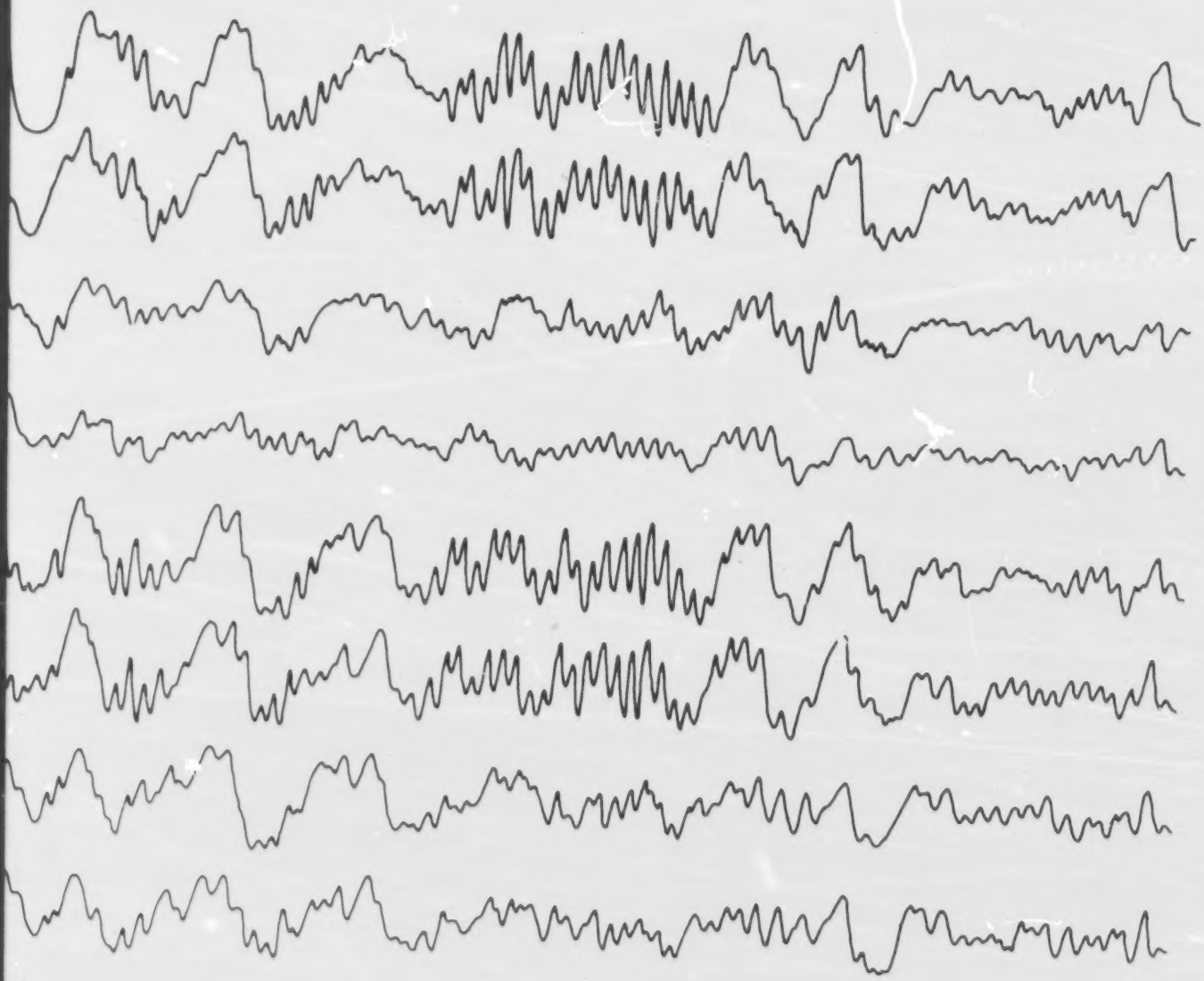
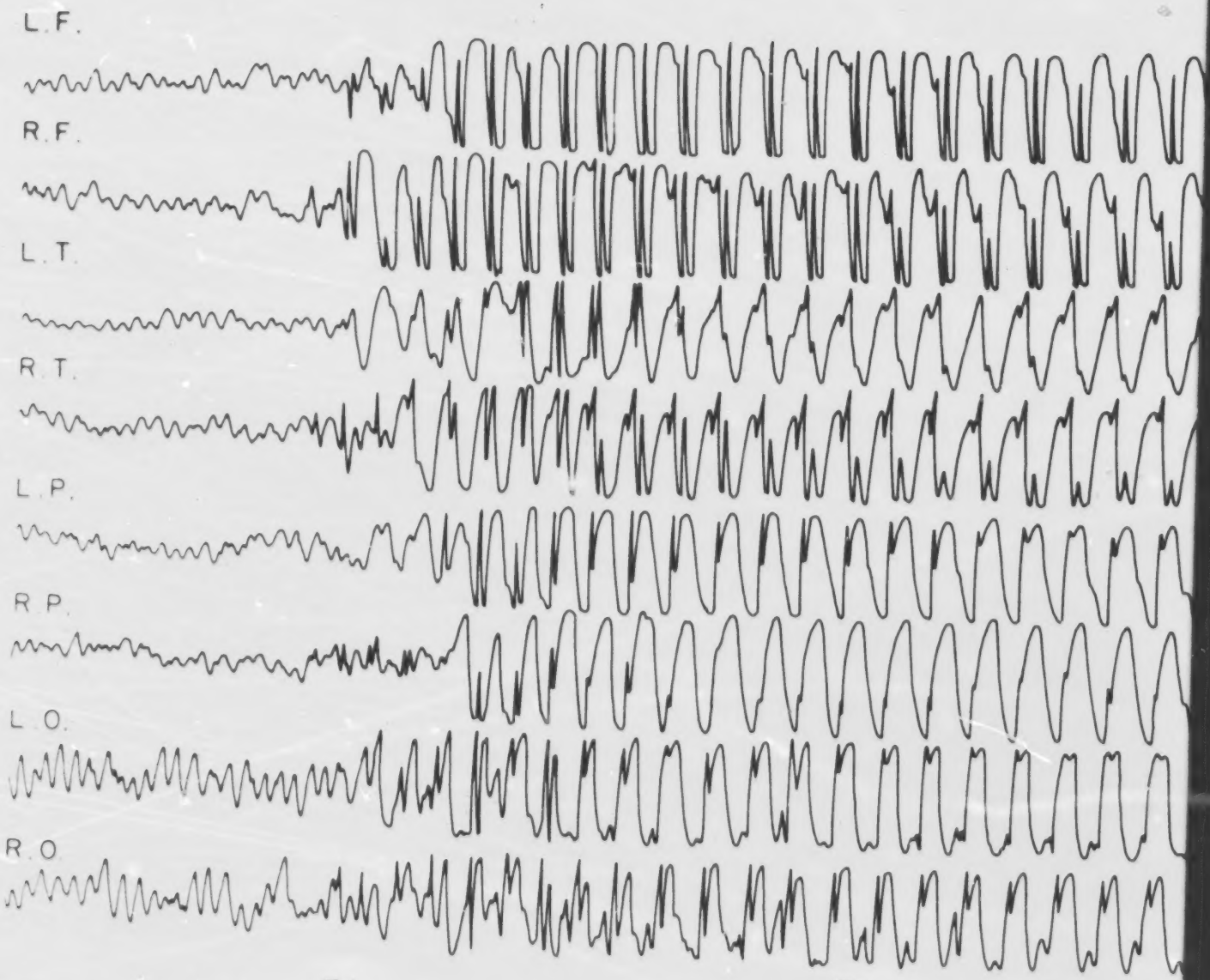


Fig. 2



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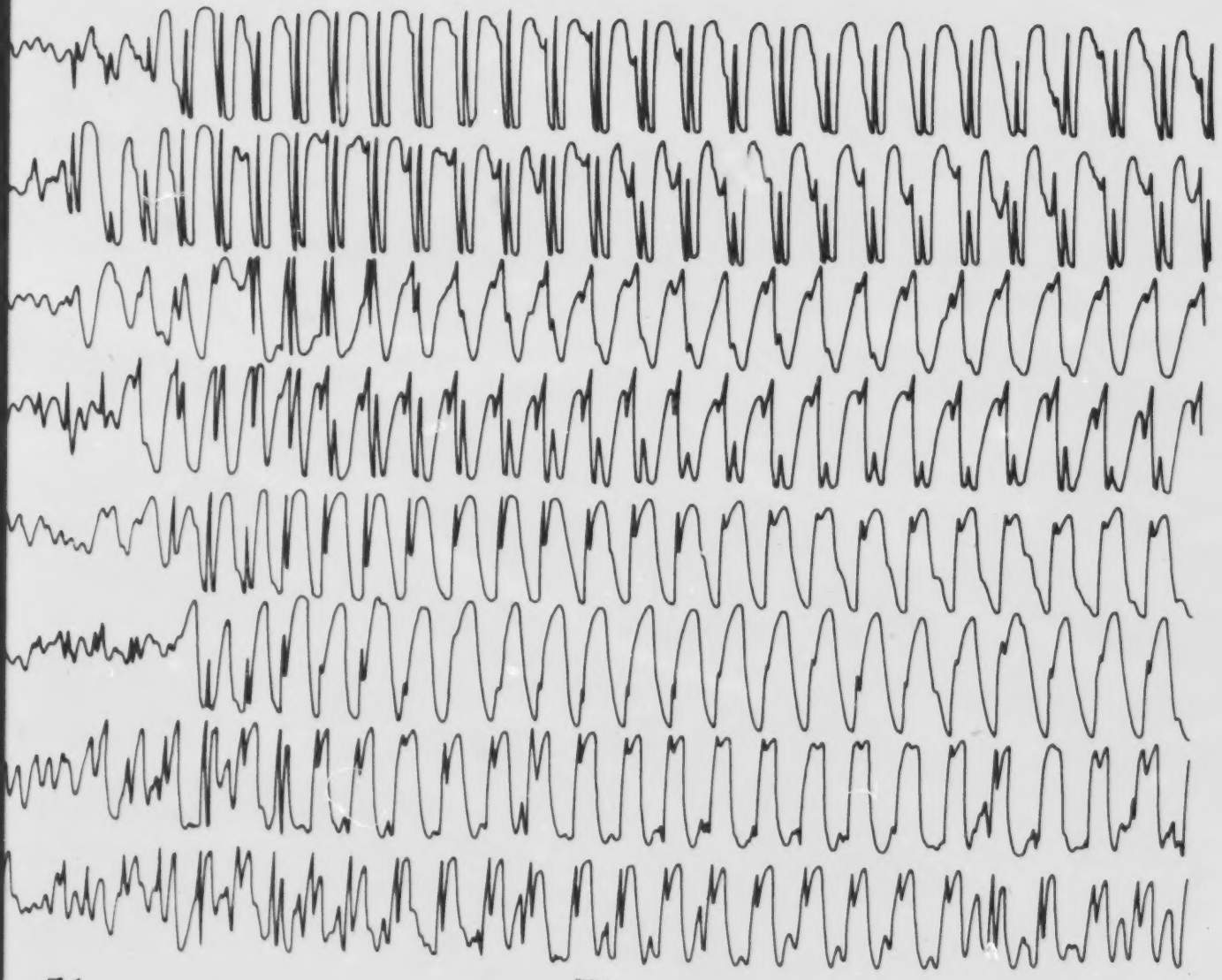


Fig. 3

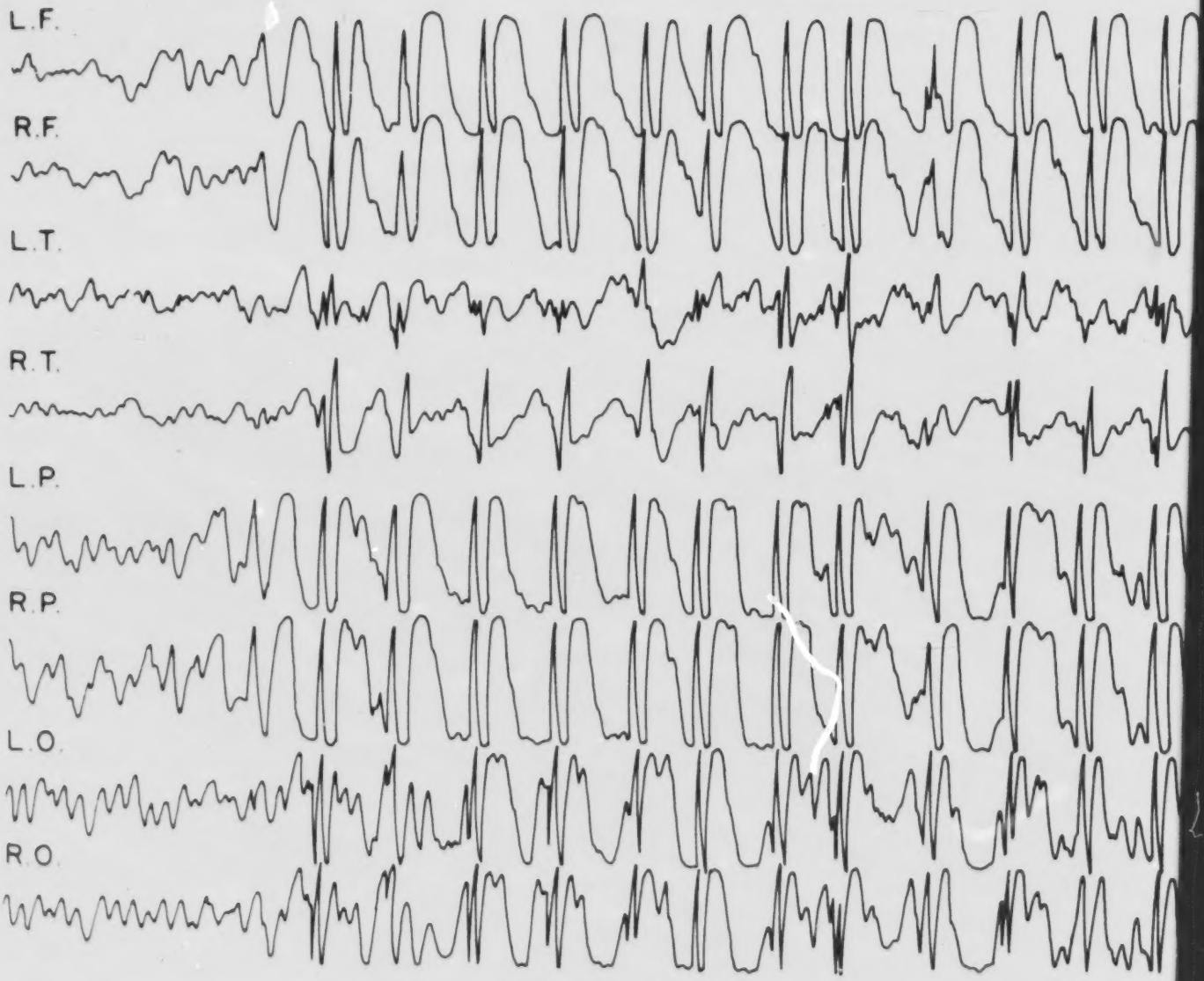
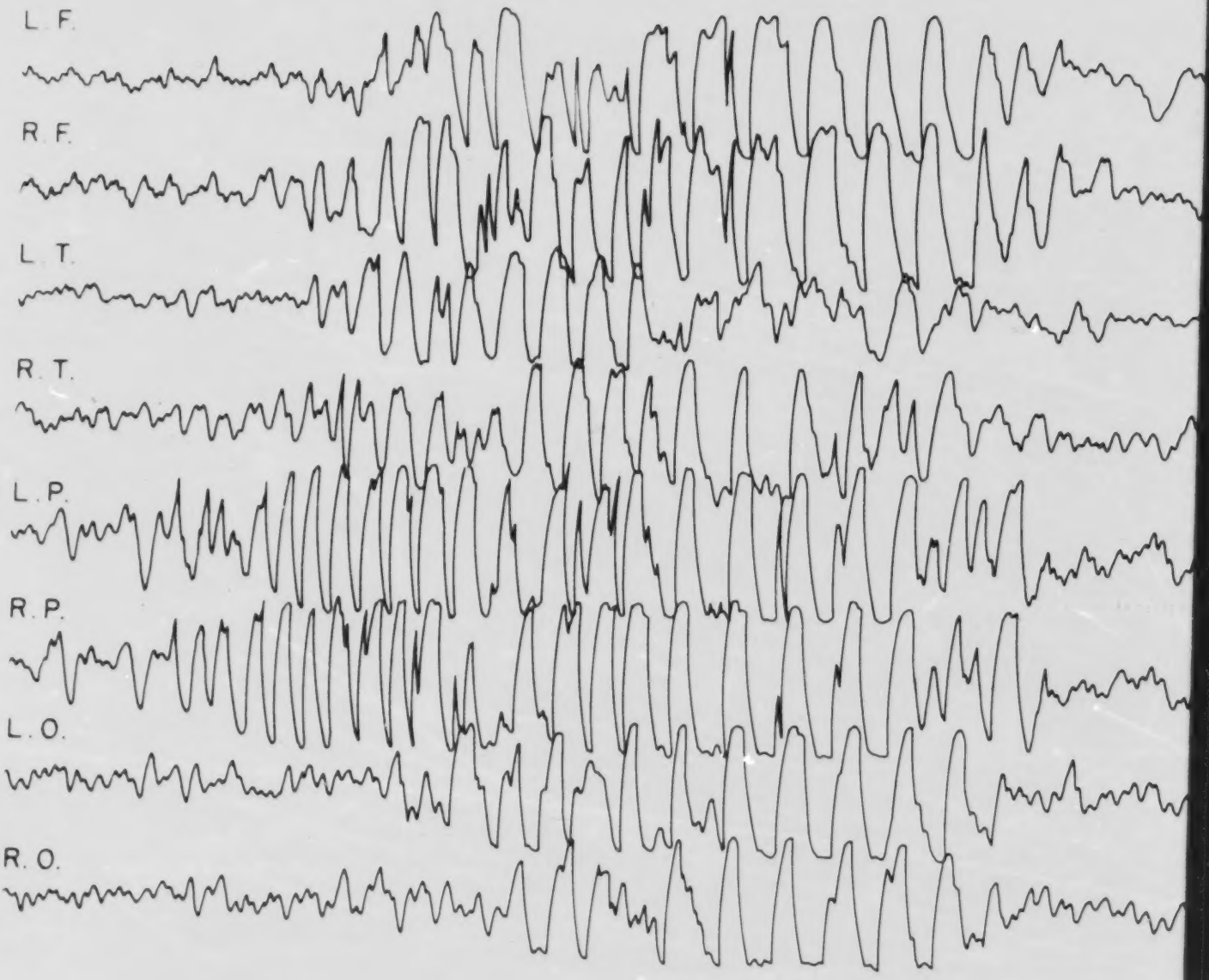

L.F.
R.F.
L.T.
R.T.
L.P.
R.P.
L.O.
R.O.

Fig. 4


L. F.
R. F.
L. T.
R. T.
L. P.
R. P.
L. O.
R. O.
50
60
61

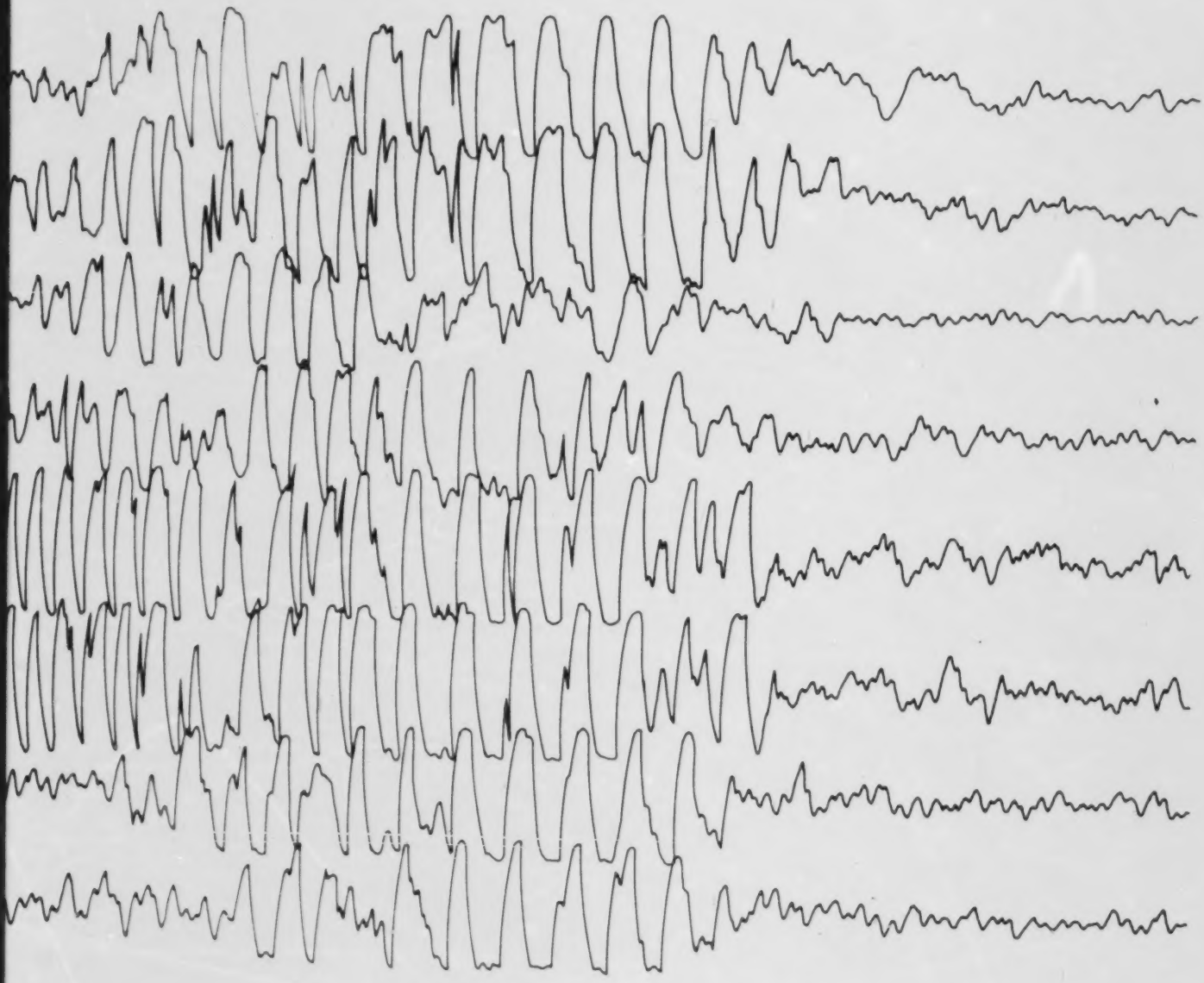
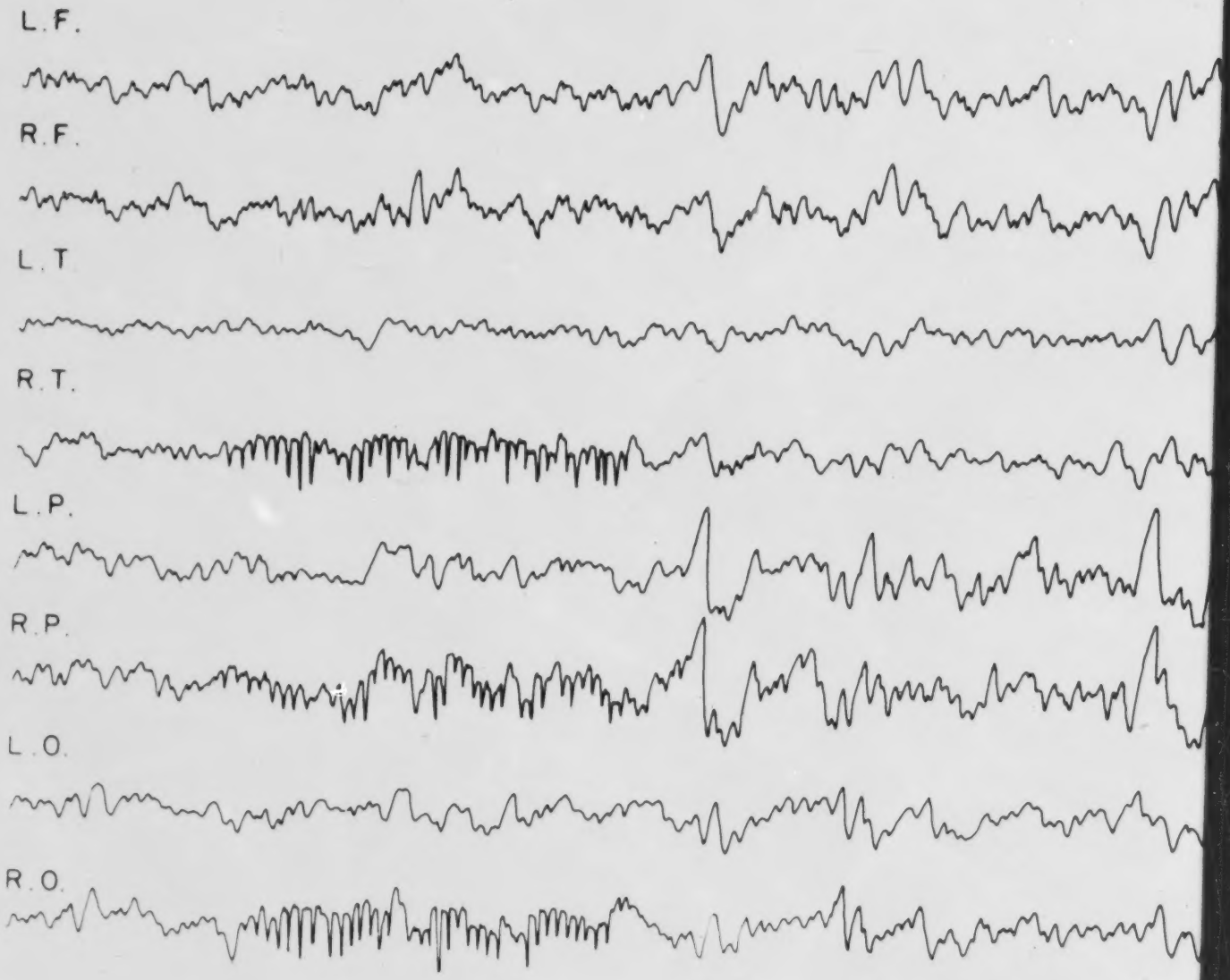


Fig. 5



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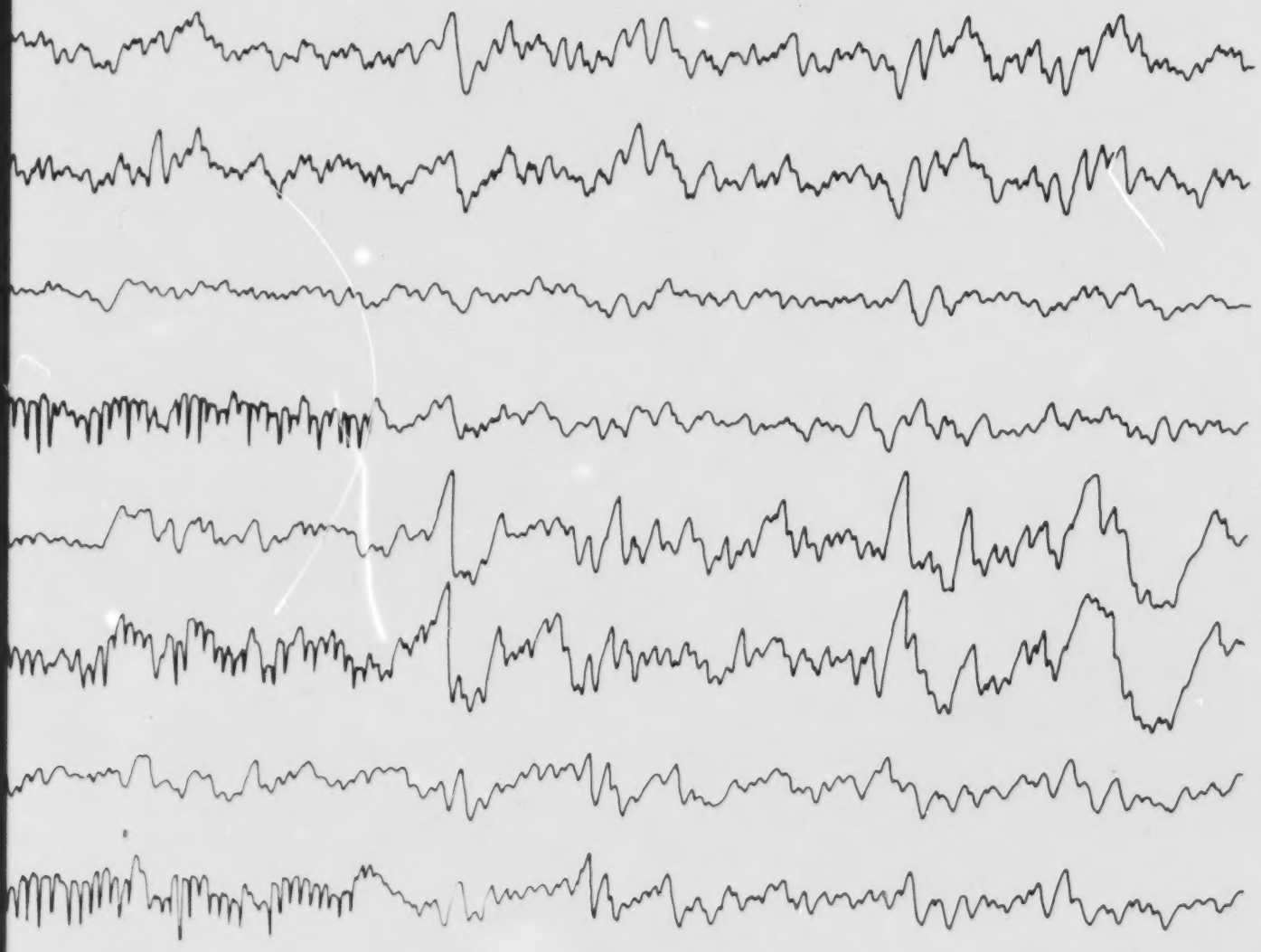
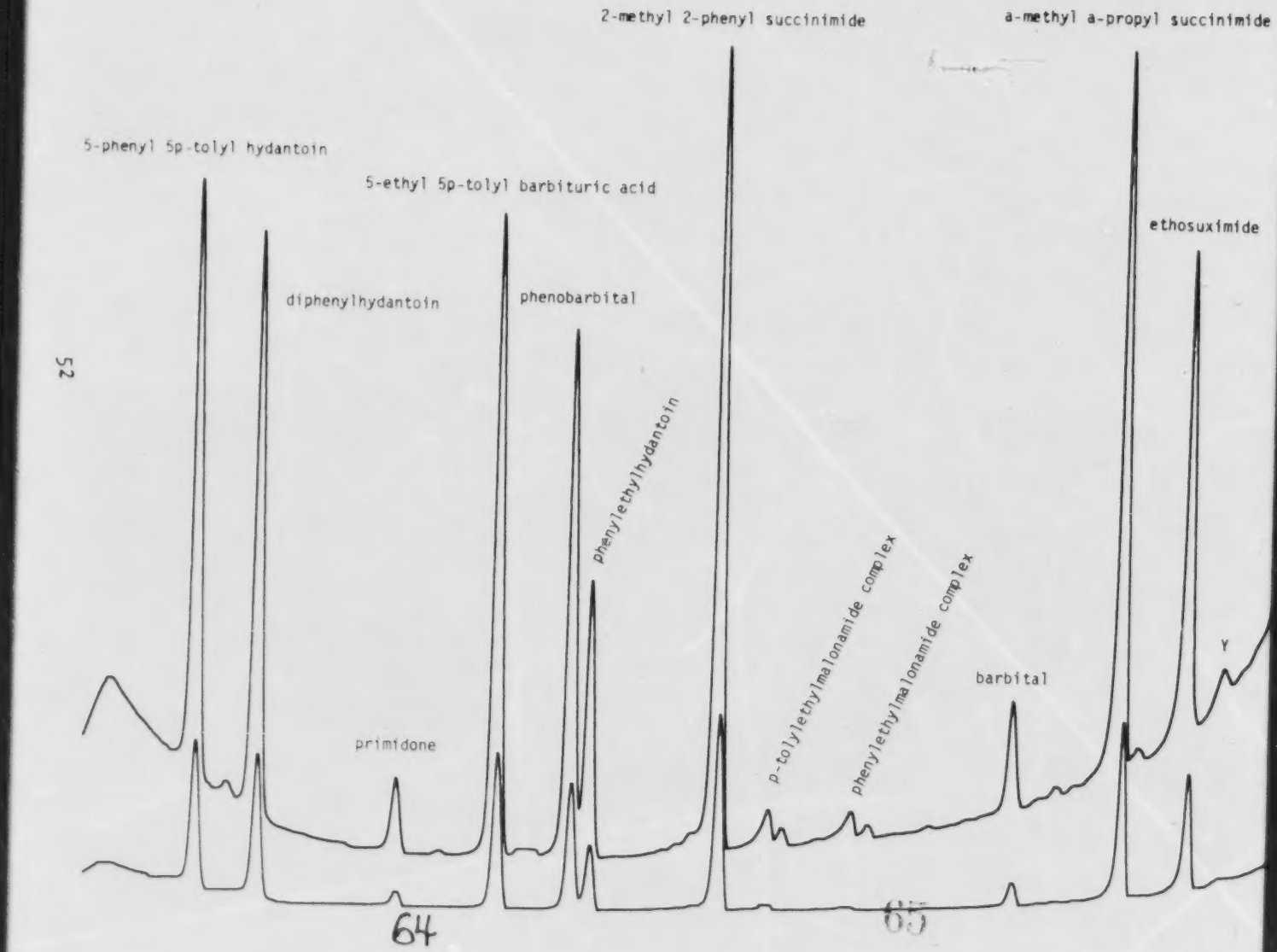


Fig. 6


2-methyl 2-phenyl succinimide
a-methyl a-propyl succinimide
5-phenyl 5p-tolyl hydantoin
5-ethyl 5p-tolyl barbituric acid
ethosuximide
diphenylhydantoin
phenobarbital
phenylethylhydantoin
p-tolylethylmalonamide complex
phenylethylmalonamide complex
barbital
primidone
Y
52
64
65

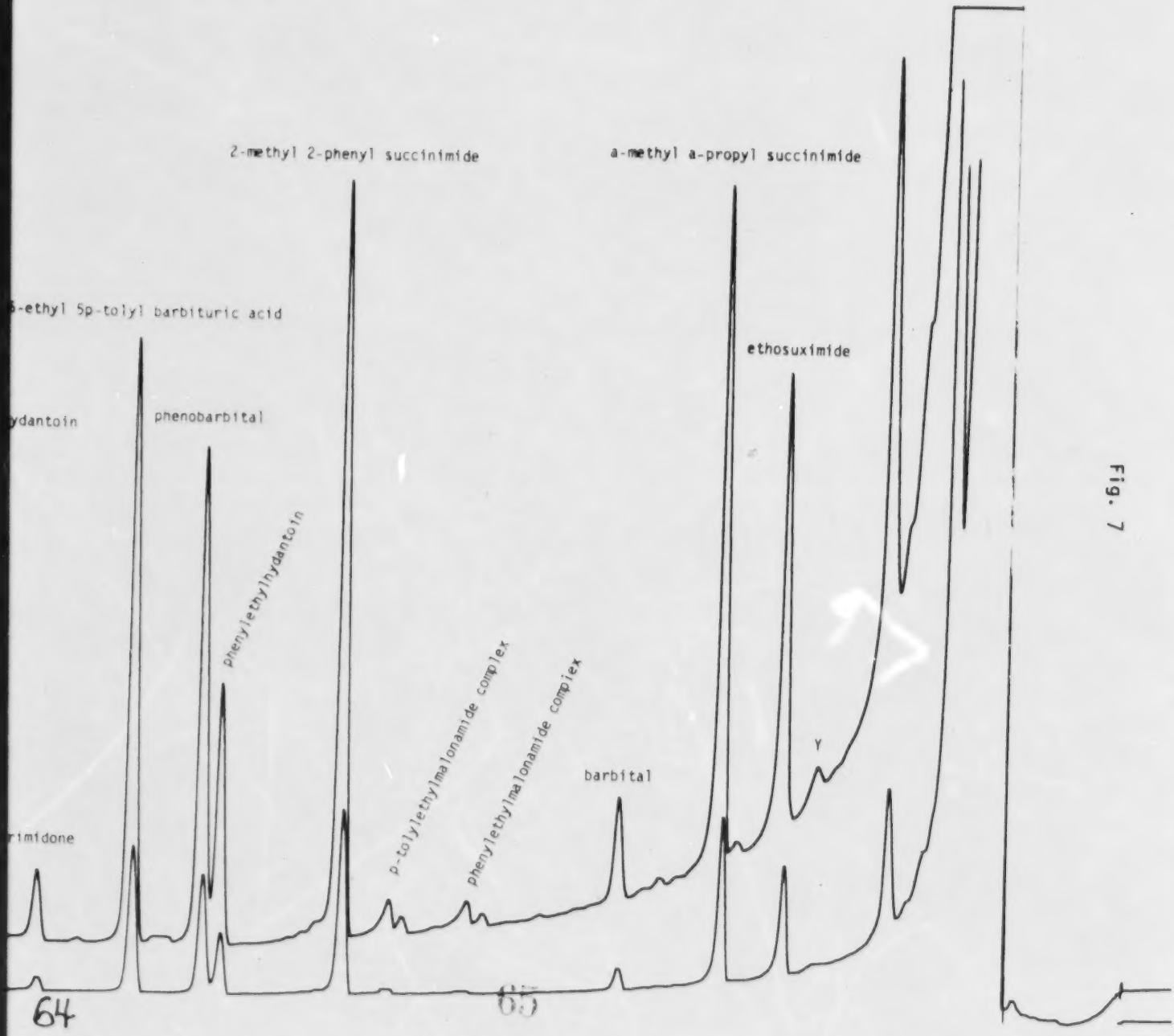

2-methyl 2-phenyl succinimide
a-methyl a-propyl succinimide
5-ethyl 5p-tolyl barbituric acid
ethosuximide
ydantoin
phenobarbital
phenylethylhydantoin
p-tolylethylmalonamide complex
phenylethylmalonamide complex
barbital
Y
rimidone
64
65

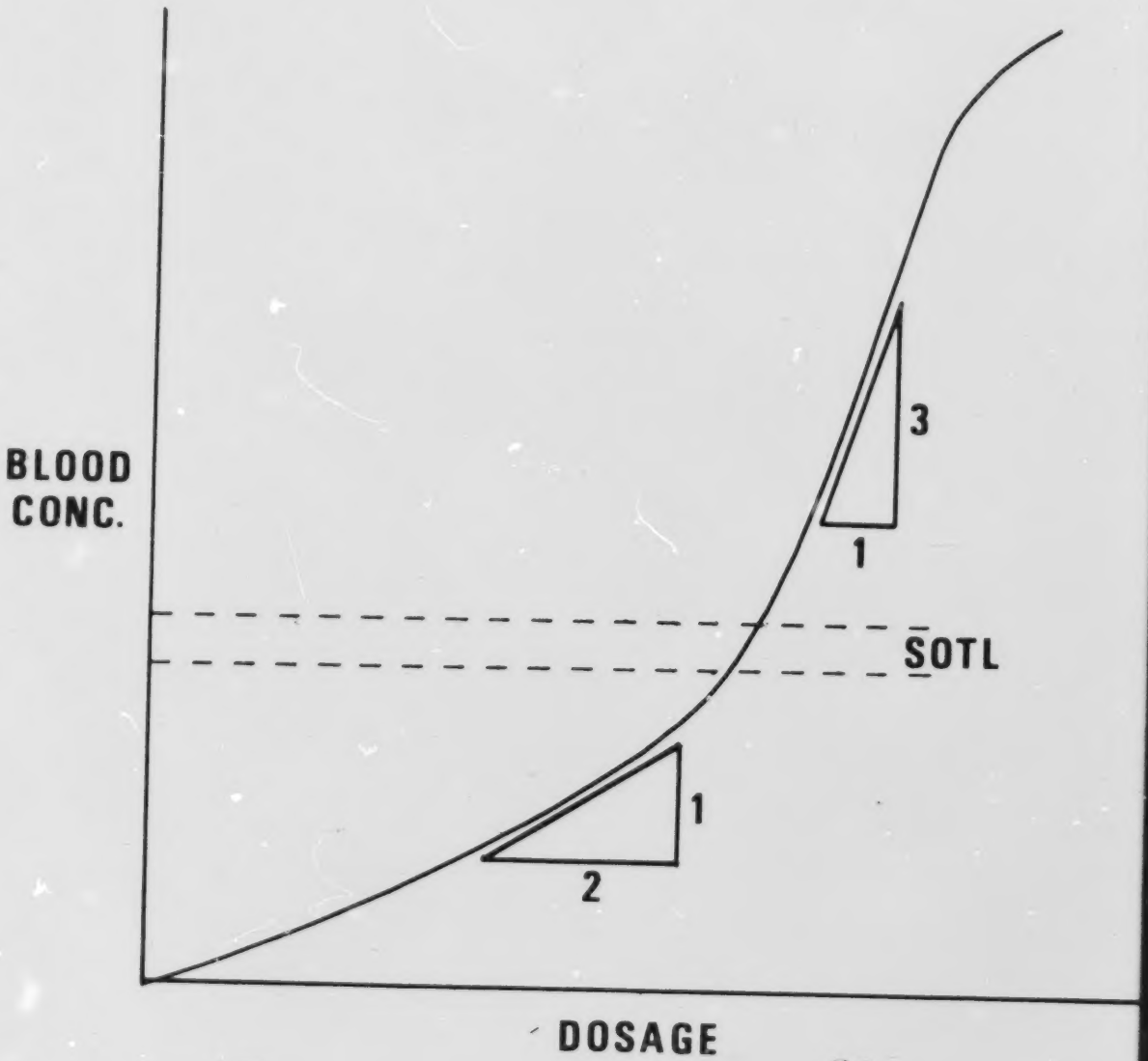
Fig. 7

Fig. 8

Anti-Epileptic Drug Determinations

The following drugs are determined by GLC methodology:

diphenylhydantoin	(Dilantin)
mephenytoin	(Mesantoin)
phenylethylhydantoin	(Nirvanol)
ethotoin	(Peganone)
methetoin	(Deltoin)
phenobarbital	
mephobarbital	(Mebaral)
metharbital	(Gemonil)
barbital	
primidone	(Mysoline)
butabarbital	(Butisol)
ethosuximide	(Zarontin)
methsuximide	(Celontin)
phensuximide	(Milontin)
N desmethyl-methsuximide	
N desmethyl-phensuximide	
di benzoazepine	(Tegretol)


DIPHENYLHYDANTOIN
BLOOD CONC.
3
1
SOTL
1
2
DOSAGE

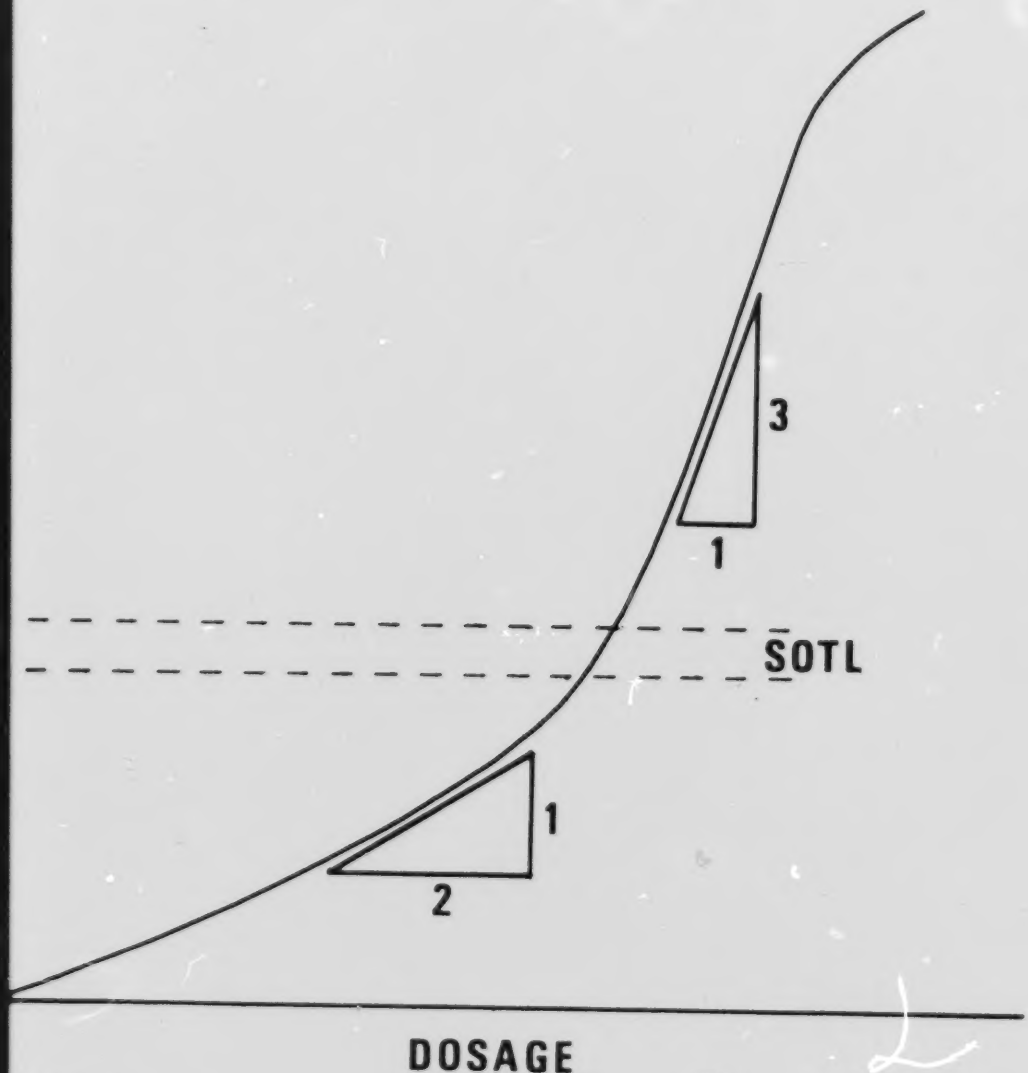
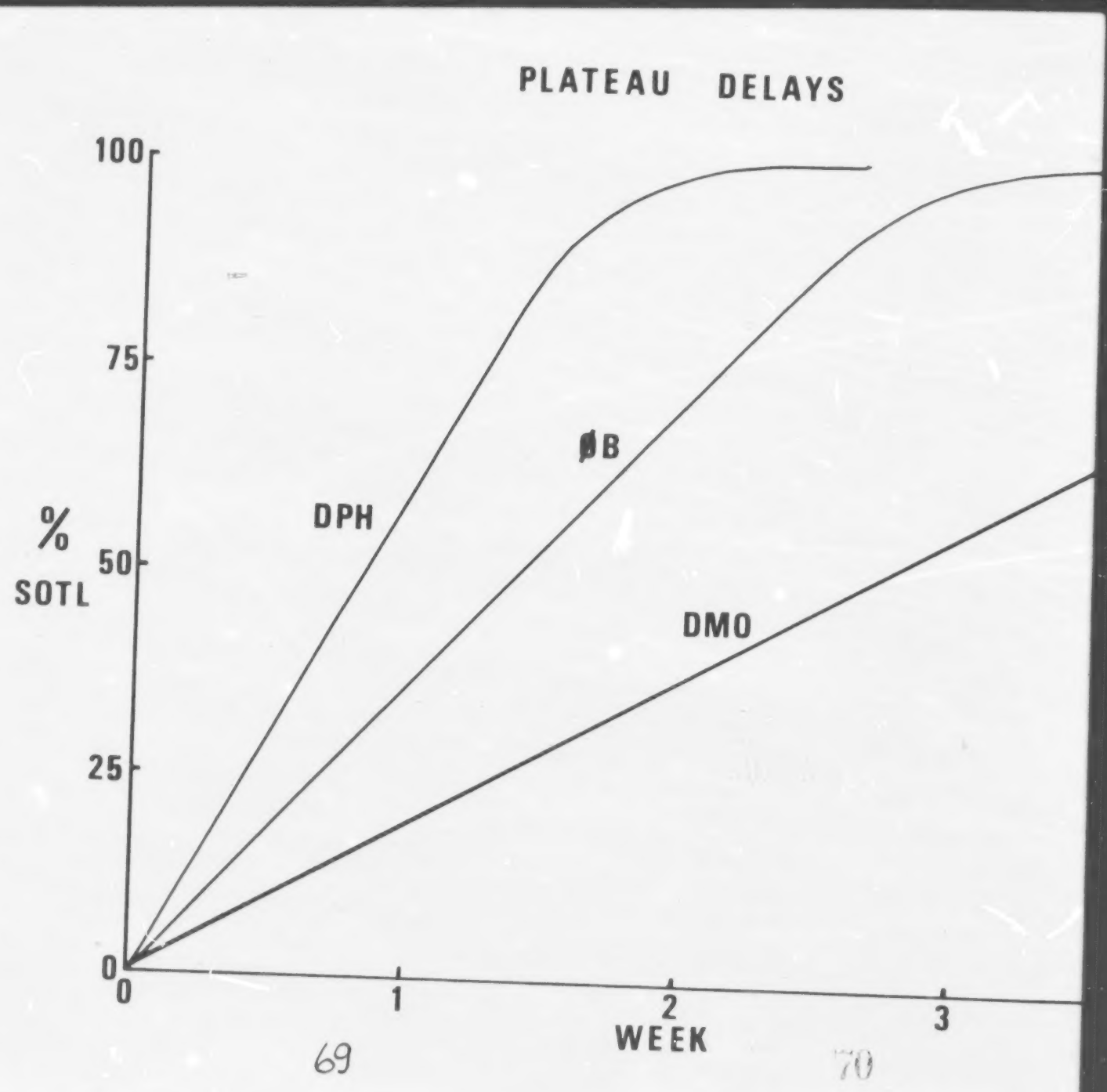


Fig. 9


PLATEAU DELAYS
100
75
50
25
0
% SOTL
DPH
ØB
DMO
0
1
2
3
WEEK

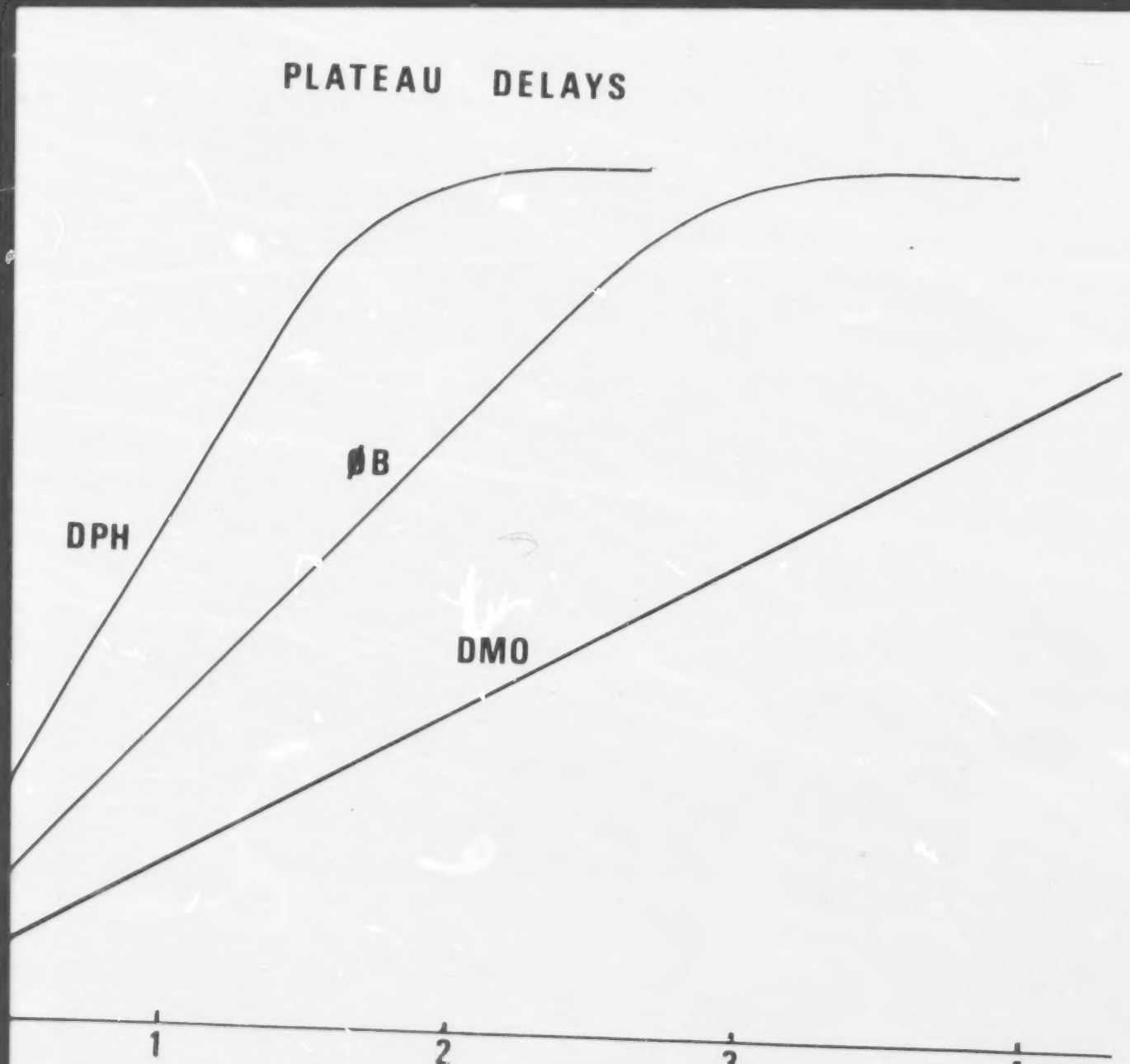


Fig. 10

Fig. 11

ANTI-EPILEPSY DRUG BLOOD LEVEL DETERMINATIONS

WHEN

DURING PERIODS OF MEDICATION CHANGE

AT 2 AND 4 WEEKS AFTER ANY DOSAGE OR MEDICATION CHANGE (INCLUDING BIRTH CONTROL MEDICATIONS, CHRONICALLY EMPOLYED ANTACIDS OR LAXATIVES, ETC.)

IMMEDIATELY, IF THERE IS A QUESTION OF SIDE EFFECTS

ROUTINELY

AT 2-3 MONTH INTERVALS IN CONJUNCTION WITH A CBC

IMMEDIATELY, IF THERE IS A MARKED REDUCTION OF SEIZURE CONTROL OR QUESTION OF SIDE EFFECTS

IN PREGNANCY*

AT 1 MONTH INTERVALS DURING PREGNANCY TO CORRECT FOR INCREASING DRUG REQUIREMENTS

AT DELIVERY: CORD SAMPLE AND MATERNAL SAMPLE

AT 2 WEEK INTERVALS FOLLOWING DELIVERY TO PREVENT DRUG BLOOD CONCENTRATION OVERSHOOT DUE TO DECLINING DRUG REQUIREMENTS

*ALL DETERMINATIONS ASSOCIATED WITH PREGNANCY ARE CURRENTLY PERFORMED AT NO CHARGE

Fig. 11

THIS HISTORY WILL BE COPIED AND RETURNED FOR YOUR FILES

TODAY'S DATE: _____ PHYSICIAN'S NAME: _____ IN-PATIENT? _____

PATIENT'S NAME: _____ HOSPITAL ID # _____

PHONE _____ BIRTH DATE: _____ SEX _____ WEIGHT: _____

HOSPITAL OR HOME ADDRESS: _____

MEDICATION

LIST ALL MEDICATIONS, FORM OF MEDICATION, DOSAGES (INCLUDING ASPIRIN, BIRTH CONTROL PILLS, ETC., IF TAKEN REGULARLY OR TODAY OR YESTERDAY) AND ROUTE OF ADMINISTRATION. HOW LONG HAS THE PATIENT BEEN TAKING THESE MEDICINES? DOES THE PATIENT TAKE MEDICINES RELIABLY OR IS THE MEDICATION HOSPITAL-ADMINISTERED

IS THE PATIENT EXHIBITING ANY SIDE EFFECTS FROM THE ANTI-CONVULSANTS? (I.e., Reduced Perspicacity, Nystagmus, Ataxia, Thick Speech, Lethargy, Hirsutism, Hyperplasia of Gums, Blood Changes, Rashes, Excited Behavior, etc.)

CURRENT CLINICAL

TO WHAT EXTENT HAVE THE PRESENT MEDICINES OR MEDICATION CHANGES HELPED? (I.e., increased or decreased frequency of spells, spells more or less severe, increase or decrease of side effects, etc.) PLEASE BE SPECIFIC

REPEAT DETERMINATION: NO: ____ YES - Date: _____ (Please supply results if not performed by our laboratory)

IF YES, DO NOT FILL OUT "HISTORY" BLANKS UNLESS SOMETHING NEW HAS COME TO LIGHT. (I.e., current EEG, new illness, etc.)

HISTORY:

IS THE PATIENT MENTALLY NORMAL, DULL-NORMAL, DULL, OR RETARDED?

DESCRIBE CONVULSIONS OR SPELLS THE PATIENT HAD BEFORE BEGINNING MEDICATION: (I.e., facial with lip-smacking and confusional episodes, blinking-staring with no post-ictal aura, blackouts, stomach aches with palor and occasional vomiting, etc.)

ETIOLOGY?

WHAT ANTI-EPILEPSY MEDICATIONS HAVE BEEN TRIED PREVIOUSLY (dosage?) AND WITH WHAT RESULTS?

WHAT IS THE EEG IMPRESSION? WHERE AND WHEN WAS THE EEG TAKEN? PLEASE USE THE LANGUAGE OF THE EEG REPORT "IMPRESSION".

ARE THERE ANY OTHER COMPLICATING MEDICAL CIRCUMSTANCES? (I.e., other disorders? Pregnancy, etc.?)

Figures

1-6. No legends.

7. A typical Gas-Liquid-Chromatographic scan of Anti-Epilepsy Drugs using Method pHA-Tol-73. The use of three internal standards greatly reduces the error and makes reporting results to within 5% routine in most cases.

8. List of Anti-Epilepsy Drugs currently determined by Gibbs Laboratories.

9. The dosage-response curve for diphenylhydantoin is extremely non-linear and variable from individual to individual. This "average" curve helps to explain how small dosage changes can produce large blood concentration changes when a patient's blood levels are close to the SOTL (Suggested Optimum Therapeutic Range). Some anti-epilepsy drugs have more linear dosage-response curves.

10. Typical rate of rise for the blood concentrations of three anti-epilepsy drugs. In these cases, it is assumed that "average" patients were placed on oral maintenance doses that would result in a final blood concentration within the SOTL range for each of the drugs.
DPH = diphenyhydantoin; øB - phenobarbital; DMO = dimethyloxazolidine dione (the major metabolite of Tridione).
It is apparent that a therapeutic or plateau blood level response to a drug change or dosage change cannot be expected immediately in the case of most commonly used anti-epilepsy medications.
Blood levels of anti-epilepsy drugs will also rise slowly even if a patient is given the drug intravenously.

11. No legend.

12. No legend.

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EPILEPSY FROM THE CONSUMER'S VIEWPOINT

Community and Professional Education

Judith Lester
Program Director
Greater Cleveland Chapter
Epilepsy Foundation of America

The voluntary organizations today are usually set up to provide two sets of services if they are fortunate enough to have money, and can hire staff. They provide social services, and also a program of what we consider to be community education.

In using the term "voluntary" organizations, I mean in this instance non-public organizations that are set up in the field to provide services to individuals with epilepsy and their families. By "social services," I mean dealing with the emotional, social and vocational problems that are causing concern to the individual and his or her family. By "community education," I mean parent and patient counseling or what we consider epilepsy education. The organizations provide education in order to change the attitudes of the general public, and education for professionals to give them a better understanding of the kinds of individuals they will be dealing with. By "professionals," I mean social workers, vocational counselors, teachers and nurses.

It is my opinion that in the future there will be a movement away from agencies providing direct services, and toward a stronger emphasis on community education and advocacy. There are a number of reasons for this. First, if we do our job properly, in terms of community education, there will be a significant reduction in the numbers of individuals who need direct services. Second, with the shortage of money, which will probably continue, agencies are going to be really hard pressed to find community dollars to support their programs.

Therefore, since there are tremendous service networks already set up, with the manpower, the professional expertise and the money -- whether they are state agencies, other voluntaries, such as family service associations, centers for human services, or perhaps a hospital complex with a large social service department -- we must learn to better utilize the services we have, because although there will come a time when the need for them is reduced, there will still be some individuals who will need a certain number of services. If we do not use our present services better, we will not have the money to continue to provide them, or to expand.

As far as community education is concerned, there is going to be a tremendous emphasis on the three areas I mentioned, parent-patient education, community or general public education, and professional education.

One of the things we see in dealing with all sorts of children and adults daily is that very often they have gone off the track right from the very beginning at the point of diagnosis. Sometimes there are good reasons for this. For example, let us say that a patient attends an outpatient clinic where he has to see a different doctor every time. He has to wait eight hours to see a doctor, and then that doctor is allowed to

spend five minutes explaining the actual problem: "Your child has a seizure disorder. This is the treatment involved...Come back in so many weeks, or months... This is what you should do... Get back in touch with me."

All well and good. But individuals have not forgotten the historical implications of epilepsy, and it is an extremely traumatic situation to be told that a child or teenager or fellow adult is having this problem. It is at this point that counseling is needed. It should be part of the treatment process. It does not matter who does it; probably the physician's time can be better used, but there must be some support services in terms of counseling.

In Cleveland we have been sending individuals into a number of different inner city out-patient, pediatric and adult out-patient clinics. It has been our experience that the earlier we get involved in counseling, the better. Often someone may come to us ten years later, but our effectiveness is usually not as significant then as if we had had access to the people at the point of diagnosis. By providing the staff people to go into these clinics, we have been there when individuals are diagnosed. We also provide a staff person to talk to those people who perhaps have not seen the need to go to the clinic every time, or to see that their child's prescription is refilled, because of the long wait involved. This staff person can explain the importance of good medical control in terms of that child's future.

We have been more mobile than some of the other individuals in the hospital by going into the home and seeing what kinds of problems exist there, and encouraging the family to utilize our service if they encounter difficulties with the schools or with vocational careers or with any other problems that might arise. This has really been beneficial.

It is certainly possible that there will be individuals with very complicated problems who come to us later on. Sometimes we can effect change with these people, especially if the problem is vocational or, in the case of a young adult, by getting him involved in a group situation with other young adults who have overcome their difficulties. Generally, however, we recommend that counseling as a part of the treatment process should become a nationwide policy. Sometimes a private physician does not have an opportunity to sit down and answer all the parent's questions. In fact, the parent may think of a great number of questions after he has left the physician's office, or in the days that follow.

We do find that once they know we exist and we will talk to them, they come back to us any time they want. They can leave a message if it is at night and we call them first thing in the morning. We are located in a facility that is open seven days a week, so people can get hold of us all the time, and this has been extremely beneficial in changing the situation of the family.

People have not forgotten that we used to institutionalize, sterilize, and discriminate educationally against individuals with epilepsy. We had workmen's compensation laws that discriminated against them, and they think this is what lies ahead for their child and it is very upsetting to them.

If this is allowed to happen, often we see certain things occur. First, the family begins to over-protect, or reject, or deny that the condition exists. Often we find families that suddenly do not talk about epilepsy; they say the child is not taking anti-convulsants, he is taking vitamins or pills for an allergy or some other condition. Perhaps parents are not getting the drugs because they have heard they are extremely powerful medications and they do not want their child taking them on a regular basis. Unfortunately they have never discussed this with anybody. Sometimes there is a situation where a brother or sister suddenly has to start walking that child to and from school all the time.

We try to see that the individual leads as normal a life as possible so that emotional problems will not develop later on. We encourage parents to treat the child as normally as possible in every way and not to restrict activities except on specific instructions from a physician. All of this education should mean that all the services we provide today will not be necessary in the future.

The first opportunity for the child or individual with epilepsy to go off the track is in his initial contact with parent or other family member. Then we have to educate the other individuals in the general community with whom that child or adult will come in contact. This means constantly providing programs of education whether for the PTA or Kiwannis, or information to the media. It is an ongoing problem in a program like ours, to see that new information is constantly available to the general public. I do not think everybody out there is non-receptive; they just do not know all the new information that is available on the subject. They need to know so that that individual or child will not be rejected in terms of his social experience with other.

The other area where education is needed is among professionals, by which I mean in the first instance teachers. Very few teachers are ever provided with the kind of information they need for a classroom situation. Perhaps they have heard of a convulsion, they may have seen one, but very seldom are they provided with the information they need, especially in the case of minor, more subtle types of seizures that can go undetected for a period of time.

We need to educate teachers to help us in early detection of school-children with epilepsy. We also need them to help us from a public relations standpoint. If information has been provided about a particular child on a health card, then if that child has a seizure or some noticeable problem at school, the teacher can explain to the other children exactly what is going on, and explain it in a positive way. Also, if the teachers are aware of agencies like ours, they can provide information for referral purposes to families, so that families reach us for different sorts of counseling or services. This is a tremendous need.

If we are to turn to social workers and vocational counselors to provide certain kinds of services, they too must be properly informed in order to provide those services. I do not think they get the necessary information as yet.

Nurses have been extremely helpful to us, because in the area of

special services or specialists, they have referred people to our agencies for early counseling. Pediatricians, internists, other groups, have not done this. We have found that nurses have been helpful in seeing that individuals understand that all sorts of services exist, and that they come to us. So they must be fully informed on the different sorts of problems that exist.

One thing we must plan for in the future is residential services. With the emphasis on developmental disabilities, the multi-handicapped individuals, with information coming from Washington on all the new programs, we have a number of individuals coming back to the community who have been sent to institutions in the past because they simply had a seizure problem. This is a population we really do not understand very well. They may have been placed in a state institution fifteen or twenty years ago because of this seizure problem, and now they are returning to the community.

Where do they go? What kind of services are we going to be able to provide for them? They might not fit the category of strictly cerebral palsied or strictly mentally retarded, in terms of residential alternatives, nor should they. We have had a number of individuals brought to our attention we did not know what to do with because the residential alternatives in our community were a couple of facilities for cerebral palsied individuals and a couple of group homes for individuals who fit into the classification of mentally retarded. People planning for these individuals are asking us, "What are you going to do with them?" They have no families to go back to, or the families do not want to accept the responsibility for them.

I do not have the answers. I do not know if we should set up group homes specifically for them. Since we have not dealt with that particular population, we just do not have the proper expertise to plan for them. Some of us are learning through our association with developmental disability, but many of us do not have the information available. It is vital that we address ourselves to this problem.

DISCUSSION

Member: What is the background for these counselors you send into a clinic?

Ms. Lester: One has a B.A. degree in social work, another a master's degree in social work, and we have employed a vocational counselor with a master's degree in vocational rehabilitation. But we are beginning to learn that the kinds of services they are providing are not direct case work services. They are what we consider to be advocacy, seeing to it that people eligible for services get them, seeing that they do not get lost along the way, seeing that we meet whatever needs they have as a family or as an individual. They do not always require professional expertise.

Member: In other words, in groups not as well funded, they could be knowledgeable volunteers.

Ms. Lester: Yes, they could.

Member: We have had a program going at the University of Illinois for three years, trying to improve the efficiency of the clinic, and we have been asking repeatedly for someone with just the kind of status you outline as a go-between the busy physician and the patient.

Ms. Lester: This was set up by two pediatric neurologists. They requested it.

One of the important functions this person fills is to find out why patients do not come to the clinic regularly. Most of the time it is because they have seen a different doctor every time, or because it has taken so long to be seen. Possibly as a result the clinics can re-assess their programs and make them more effective.

Member: There is another big problem we are running into now, and that is the cost of going to the clinic. Initially, the person may have to go two, three times a month, and he needs EEGs, blood tests, et cetera. He goes once or twice and runs up a bill of $200.00 or so and cannot go back because he cannot pay the first bill. He doesn't tell the doctor this. So now we are beginning to intercede with the credit department and set up a system, educating the credit department to the fact that although the patient has built up this large bill it will taper off. We ask them to make some kind of arrangement.

Ms. Lester: It is surprising, with this new supplemental security income, how many people do not realize what they are eligible for, or how many are turned down at the point of entry when theyare really eligible. Again, that is the role of advocacy.

Dr. B. Boshes: Ms. Lester has opened up what I consider the most germane area of the problems in epilepsy. As we teach our students in medical school, and as we meet medical groups, we are inclined to say that the treatment of epilepsy is this or that drug, this or that surgical procedure, but actually the treatment of epilepsy is what Ms. Lester has been talking about and what the rest of the afternoon is going to be devoted to.

I have dealt in public relations and public information in the field of epilepsy for the better part of a generation. Ms. Lester mentioned laws about sterilization. Not too many years ago, in seventeen states a person with epilepsy could not marry. In six states, anyone with epilepsy was sterilized as soon as the diagnosis could be established. This is in the United States. A person who had seizures could not emigrate from another country into the United States. And even to this day, how many medical schools will accept a person who has a history of 3-per-second spike and wave in early childhood?

Dr. B. Boshes: (cont.) Curiously, we have had much more luck with industry than we have had with people in education, who are the allegedly enlightened ones. So that although the impairment is the recurrent loss of consciousness associated sometimes with a convulsion, sometimes with an "absence," sometimes with a period of automatism, the real disability is to take this impairment, sometimes rendered down to almost nothing, and put it in the context of trying to get an education, trying to get a job, trying to find one's place in the social milieu.

A year ago last March, at the Western Epilepsy Institute, a curious question arose. If one hundred epileptics are working in industry and lose their jobs, how many lose their jobs because they have had a convulsion or modified convulsion on the job? A seizure or something like a seizure? It is interesting that the figure is only twelve percent. Eighty-eight percent lose their jobs because they come to work angry, they are unhappy with their families, in their social milieu, have had a fight with their spouse, parent, children, something has upset them because they are still pariahs in their families, and in their communities.

This is why the subjects of this afternoon are so very, very important, and how important you people are.

I would like to ask Mr. Lester one question. She spoke of "we" in Cleveland. Where are "we" located? Are you in a building, an office, at the end of a telephone? Are you peripatetic? Are you in one place? You said you are open seven days and seven nights. Where is "we?"

Ms. Lester: We are located in the Cleveland Health Museum and Education Center. It is open to the public seven days a week and has on display a whole city block of health education exhibits.

Dr. B. Boshes: How many hours are you there?

Ms. Lester: Usually from eight-thirty to five, Monday through Friday, but there is always somebody there up to five o'clock seven days a week, and then there is an answering service.

Dr. Boshes: It is enormously important to have a place where the information can be started. It allays the anxiety, at least pulls the plug, and this is very, very important.

Employment Experiences

Carol Lawless
Jewish Vocational Services
Chicago, Illinois

I am going to take a more global approach to the problem of job experiences rather than describing persons with epilepsy who have had difficulty finding or keeping jobs, or listing the types of jobs for which persons with epilepsy do not qualify.

Aristotle commented once that honor is more in those who do the honoring than in those who are honored. In other words, if honor is a recognition of worth or value in another person, then honor is more in the one who does the recognizing than in the one who is recognized.

In general, we do not have too many heroes in our society. A relationship involving honor is fairly rare, and it is very difficult. Consider, for example, an Einstein or perhaps a Rose Kennedy. Suppose one were at a party and saw Einstein standing on the other side of the room. One would probably pause before walking across the room to shake hands and start talking about the weather.

Aristotle's insight is an ancient one. A more contemporary one is that of Irving Goffman, who wrote the book Stigma. It is interesting to note the parallel. Goffman says, "Stigma is more on the one who does the stigmatizing than on the person who is stigmatized." That is, the person who feels that he has recognized something unworthy in another bears the stigma more than the person who is stigmatized.

A relationship involving severe stigma would also be considered a rare one and a difficult one. In terms of both honor and stigma, we are considering exceptional relationships of a public nature. It is probably fair to say that persons who have epilepsy have encountered what could very well be called stigma in their attempts to find employment. I do not want to suggest that every employer invokes stigma in dealing with a person with epilepsy but it is generally agreed that there is a problem.

How do employers relate, generally, to persons with epilepsy?

In the employment interview they tend to relate in three characteristic ways: with fear, with misunderstanding, and with prejudice. Which comes first? Is it fear of the unknown that leads to misunderstanding, and finally fossilizes into prejudice in our society or is it a long-standing prejudice that makes understanding impossible and which leads to a generalized fear? Either way, what is meant is the inability to relate to someone who is exceptional, or to enter into an exceptional relationship of a public nature. I will cite two examples.

A young man in his early twenties was hired by a company on a probationary basis, as was the policy of this company, pending a general physical examination. He had not been in the employ of the company for very long when he took the physical, and it revealed evidence of the presence of an anti-convulsant drug in his system. He had not told his

employer that he had epilepsy. The employer confronted him with the evidence, and the young man was trapped by circumstances. He tried to explain that he had epilepsy, to give the employer the name of his neurologist, and to explain that the anti-convulsant was to control seizures, but the employer would have none of it. He accused the young man of being a drug addict and dismissed him summarily.

Another young man, somewhat older, had held a series of jobs of short duration, but successfully, a year or so on each job. He had not told any of his employers that he had epilepsy, and it had not been discovered. He had not been fired from these jobs. A placement counselor advised him that the next time he went to an employment interview, he should tell the employer about his problem. He later went through a series of interviews with different employers and was turned down. The counselor contacted the employers and did some investigating. She discovered that the young man would walk into the employment interview situation, sit down, and blurt out loudly, "I have epilepsy." Naturally, the employers were petrified with fear. The counselor, therefore, worked with the young man in terms of role playing, and counseled him as to how to present himself. The next time he was able to secure a job.

These two examples are somewhat parallel. In the first instance, the employer was the one who recoiled from the relationship. He presumed that he could not relate to this young man and to something that he did not understand. In the second instance, it was the employee who recoiled from the relationship. It was the young man who presumed that the employer could not relate to him and to his problem. And, in a sense, the second young man set up a self-fulfilling prophesy, for indeed none of the employers could relate to him.

What is probably needed is re-education in terms of how to relate. We should understand, or perhaps believe, that previous mis-education may not really be anyone's fault.

There are many definitions of placement but basically, professionals say it is finding the right person for the right job. It is actually a selling process. One is selling an employer the idea that the person is in fact the right person for that job opening. Therefore, under present-day conditions, one must ask what one can sell and what can one not sell employers with regard to persons who have epilepsy.

What can one sell? One can sell the idea that it is possible to control epilepsy. One can sell the idea that people with epilepsy can be dependable. One can also sell the idea that people with epilepsy have capabilities. It is interesting to note that this last is, in a sense, the weakest selling point of all, but somehow we have begun to come out of the dark ages, and employers are willing to accept the idea.

What can one not sell to employers? In most cases, one can not sell the idea that a person with epilepsy can work with machinery. In numerous cases one cannot sell the idea that insurance risk is not extraordinary when hiring someone who has epilepsy. In most cases one cannot sell seizures, that is, one cannot sell the idea that if a person has a seizure on the job it is not the worst thing in the world.

In terms of placement of persons with epilepsy, the essential selling point, and the key to the relationship, is the issue of control. It is axiomatic in our society that people expect others to maintain control at all times and in all ways in public. This is especially true with regard to strangers or someone who is in some way different.

Suppose one were at an elegant party and had a seizure. It is very likely that one might spill one's tea in the process. But the hostess who was uncomfortable in that situation probably overlooked the fact that if a person who had allergies came in and had a fit of sneezing, he, too, would very likely spill his tea.

This problem of control may be the basis for all the other difficulties that come up in so many different ways, especially with regard to employment. The problems of machinery, insurance, fear, misunderstanding, prejudice, and the nature of the stigma with which we are dealing, is how to relate to the possibility of a loss of control. To put it another way, how does one relate to the possibility of surprise, of something sudden, of the unexpected?

In terms of the contemporary job market, employers who relate positively to persons with epilepsy seeking employment do so generally in two ways. Either they are genuinely tolerant of the possibility of seizures -- and these people would probably be classified as sympathetic employers -- or they believe that no such possibility exists. It is a sad commentary on our society that the third alternative is so rare, that is, the employer who knows that he cannot have an iron-clad guarantee but is willing to take a risk anyway.

What can be done about the current situation? I would suggest three areas for change although there are certainly many more possibilities.

First of all, immediate public education is essential. It should be carried out by doctors via the media, emphasizing the advances made in the diagnosis and treatment of epilepsy. Why should it be carried out by doctors? Because doctors are benign. Why should it be a scientific approach? Because science is infallible. Why should the advances be stressed? Because people tend to rally to the side of a potential winner, someone who can benefit from the advances.

The second area is job development. Social service agencies, and general community employment agencies, need to spend some of their time and effort on specific job development for persons with epilepsy, that is, job development done at the grass roots level, contacting the foreman on the assembly line, the personnel manager and his assistants, the immediate supervisor in the office. It is not the president of the company who will hire and fire. It is the immediate supervisor who will determine whether an individual is accepted or rejected, admired or scorned.

A third area which needs attention is that of persons with epilepsy themselves. They need to understand how to sell themselves in an employment situation. It is difficult for an individual who may have been rejected many times to walk into a situation knowing that the relationship will to some extent be one of stigma. But while it is very hard on

the prospective employee, we need to recall that it is even harder on the employer, because the definition of stigma is that it is more on the person who stigmatizes than on the person who is stigmatized.

I would suggest a 3-D approach -- diplomacy, dignity and deservedness. Any person who has ever been employed has worked through the interview by using these qualities and projecting them in a generous manner.

No one approach can even begin to remedy things, but all three, taken in tandem, can have some impact, perhaps some lasting impact, on the job market and job situation today. Hopefully, these approaches will lead to small increments of goodwill and to a cumulative effect.

In closing, what we all need to do is work toward changing the present stigma to the future honor.

DISCUSSION

Member: As a rehabilitation counselor in the State of Minnesota, I place people, and when I start talking to an employer, one of the things that inevitably comes up is insurability, and this cannot be passed over lightly. It has to be dealt with openly.

The Minnesota State Workmen's Compensation Commission has a second injury law. People with epilepsy can be registered under this law even though they do not have a second injury, but rather a presently existing condition. This registration limits the employer's liability to the first fifty-two weeks of payable compensation and the first $2,000 worth of medical bills. Anything else coming out of any injury resulting from that pre-existing condition will be paid by the State Workmen's Compensation Commission, and it does not enhance the client's employability very much.

Member: The Nebraska law has covered it for two years. They have no more responsibility to the disabled than to other employees in any careless situation within the plant. After that, it goes into the second injury.

Member: I thought that one of the problems was not so much in workmen's compensation laws but in Blue Cross and life insurance. I know these are hard things to sell. It is said that in order to get life insurance for that person they would have to pay more, and for Blue Cross they would have to pay more.

Ms. Lawless: What I was trying to convey is that it is hard to sell this to employers, regardless of the reality. Part of that may be our fault. Initially we felt that workmen's compensation did always cover disabled people on a second injury. There have been some cases where the adjudication under workmen's compensation has not really been that equitable for the employer. So there has been some reality that we

were slow to recognize, but now the second injury clause does make it possible to cover the employer on insurance.

Member: Many times when dealing with small employers, they are not completeiy aware of this either whereas the larger employers will be. The insurance companies always will be. Another provision in the Minnesota law is that an insurance company cannot use this as an issue for denying insurance to a person and they can be taken to court on that issue.

Member: What is being done about disseminating that kind of information? We are constantly running into the situation where every interview situation results in no job, even though we have these various laws.

Ms. Lawless: It can be very difficult, even if you give an employer legal statements that have come out from the State of Illinois Workmen's Compensation, for example -- materials that explain the law. There is a kind of mental block. In a situation where this problem of insurance arises, the first thing the employer does is consult his lawyer. He may get the straight story that way faster or he may not. It is a variable situation.

There has been a realistic problem here that we as professionals failed to recognize. There have been problems around individual cases of second injury where the employer had to pay. For example, if on a first injury a person had 10% disability, and then on the second injury the person lost another 10%, the employer might have to pay compensation for 20%, and that was the kind of thing that was so difficult.

Chairman B. Boshes: Ms. Lawless has entered into a very important subject.

Let me interject for a moment and describe an imaginary situation.

Here is a street crossing with absolutely no traffic coming in any direction. The light is red, against you, a pedestrian. There is a traffic policeman and you walk across that street, wave to the policeman, who nods back, and you reach the other side. I am sure that if you were to have said to the policeman, "May I cross?" he would have responded, "Don't you see the red light?"

You see the two problems, the humanistic problem and the legalistic one. This is one of the things the employer faces, with the patient with epilepsy.

It is curious that the employer as a human being may be completely compliant with the climate that we are discussing here this afternoon, but legalistically he is held frequently by his insurance carrier and by his lawyer. This is where a great deal of education must come, and it

Chairman B. Boshes: (cont.)

must come not only in terms of humanistic definitions and ideals, but in cold data: how often does a person with epilepsy foul up on the job; how often does he get hurt on the job; how often does a seizure produce a disability claim?

One of the problems is definition. You will notice that I am rather specific in what I choose to call the individual suffering from this illness. I don't think there is such a thing as an epileptic, any more than there is such a thing as a "canceric". These are people with a disturbance, but the ability of the individual with this disease is from genius to mental deficiency, there is no correlation of seizure states, seizure-like states, with intelligence or ability.

Only a few years ago the definition for epilepsy was "a disease of the brain with recurrent convulsions altering the person's consciousness and behavior and ending in moral imbecility." I remember when Mrs. Ellen Grass and I went to work on this. When we went to the publishers of the high school textbooks which contained definitions of epilepsy, we ran into all sorts of obstructions. They wanted to know what proof we had and were most unwilling to make changes. Finally we did get many of the textbooks changed. It would be worthwhile to look into the latest edition of Black's Law Dictionary and see if the definition there has been revised.

Forty years ago a patient came to see me. He was seventy-five years of age and was suffering from seizures. These came under control very rapidly, even in the pre-Dilantin era. I was doing research in some of the other drugs at the time, using big white Belgian hares. I asked him what he did, and he replied, "I'm an inventor." When I asked him what he invented, he said "Talkies." This man was actually the person who developed the talkies. He had the patents, which had been stolen from him by companies which shall be nameless. In the lawsuit that followed between Germany and the United States some four years later, this company paid $432 million for the theft. If Northwestern had had the $100,000 for the lawsuit that followed we would have been the wealthiest in the country; unfortunately it was at the height of the Depression.

I asked this man what he was doing now and he answered, "Do you see this wire? I can line up the molecules and give you everything you say, right back to you." This was in the early thirties and he had the wire recorder in his hands. I would buy the IQ of this 75-year old at any time! He was cheerful, not bitter, all he wanted was to be under seizure control so that he could earn a living and play with his wires.

Chairman B. Boehm: (cont.)

Therefore, the person with epilepsy is a normal individual who has a seizure state. He has a right in every respect to live as normal a life as possible and that means in the area of employment.

In contrast to the attitude of some employers, the attitude of employees is surprising. About two years ago, two workers from one of the large industries in the southern area of the Chicago industrial district brought in a man and said, "Doctor, do you suppose you can cut down his seizures a little?" I asked what they meant and they replied, "He has had a couple this week. It used to be once every six months, and we just wondered if you could help him." It turned out that this man was a railroad car repairman who worked under cars in the repair section, not on the tracks. He was one of the best they had. He had been on the job for thirty years and usually worked on a cradle under the car. When he had his seizure, the men would roll him out on the cradle, they knew exactly what to do with him, and as soon as the seizure was over, they would roll him back, and he would take his wrench and keep on working. All they wanted was for me to cut the seizures down a little. There was no question of this man not working; he had been on the job for thirty years, and had not missed more than half a dozen days of work in all that time.

Children in a classroom are also empathetic, and they will take care of the little girl or little boy who has the seizure, provided the teacher does not panic. The teacher is much more likely to get upset than the children who are the ones who take care of the seizure.

Sometimes the epileptic seizure is not without its benefits.

Some years ago I took care of a young man who had seizures, and he came under complete control. One day he came in looking a bit bruised, and I asked him what had happened, had he had another seizure? He said, "Oh, no. I had to do it again; I had to throw a fit for the cops." It turned out I had been so successful in stopping his seizures that he obtained a job as a driver of an automobile. This was perfectly all right; people with epilepsy have excellent driving records as regards safety. But this was in the days when the Syndicate was active here and his job was to pick up out-of-town gamblers at the airport and drive them to the gambling joint. The police had heard of this service and they picked him up. The first two times they let him out. When they arrested him the third time, they began to work him over, so he proceeded to throw a simulated grand mal seizure. One of the policemen threw a bucket of water on him and ran, and then opened the cell door and said, "Get out! We don't want you here!"

Services Needed and Services Available

Mr. Willard G. Novak *
Executive Director
Epilepsy Foundation of America
Kansas Chapter
Wichita, Kansas

Exactly three months ago today I was hired as Executive Director of the Kansas Chapter of the Epilepsy Foundation of America. Until that time, the only experience I ever had with epilepsy was about thirty-five years ago when a friend and I were hitchhiking across Texas. We were picked up by two men in a car, and as we rode along in the back seat, the passenger just in front of me suddenly reared back with his head completely behind the back of his seat, not more than a foot in front of my face, and proceeded to have a grand mal seizure. Naturally I was terrified. I wanted to run and couldn't. I have never forgotten it.

A few days ago I heard a doctor say, "Either epileptics and others with disorders are entitled to a full life of happiness, freedom, and opportunity, the same as everyone else, or they ought to have their heads pinched off in the beginning." I do believe such people are entitled to lead productive, happy lives. I also believe that people with seizure problems are normal, in fact they are more normal than many with other mental or physical problems.

People who experience seizures cannot be blamed for trying to hide their disorder when only a few centuries ago they were burned at the stake in a civilized country for having epilepsy. A few centures before that, they were referred to as possessing a special deity, being some sort of god or angel. Does that say there is something wrong with being epileptic or that something is wrong with society?

If I can bring back some memories of some of our early experiences at the Foundation, they might serve to re-inspire some of you as I have been inspired by some occurrences I have experienced in just the first few weeks of my appointment.

In Kansas we have begun a survey of this topic I am discussing, "Services Needed and Services Available". We do not have all the answers; our survey is incomplete, but we do find that the needs available and the needs unanswered vary greatly, depending on whom is being interviewed.

If one talks to doctors, nurses, clinicians, hospital staff, they say, "The greatest need is to identify, examine, test, prescribe medications, make certain the patient follows the directions," and some of them will say the number one problem of the epileptic is employment. I doubt if any of us will argue those points.

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* substituting for Mr. Hal Malone, President, Epilepsy Foundation of America, who was to have spoken on *"Legal Problems and Services."*

When we talk to the school nurses, teachers, and coaches, we get a little closer to the real problem, or the problem that most of us can work with. They say, "We treat them just as other students, that is, if their parents and family doctor allow us to. Of course, sometimes we don't know all of them, and when a new one appears or when one has his first seizure, sometimes he isn't able to continue with the normal routine as his classmates do." Is that true or is that a red flag?

A great many epileptics I have talked to agree that employment is a big problem, but so many times when families of epileptics or epileptics themselves come to us for job assistance, we find they are not qualified for any kind of job, or they do not know of any kind of job they are qualified for. Are we supposed to give them a job just because they are subject to seizures? Some of them seem to think so. I do not believe they qualify just because they are epileptic, and I do not believe we are obligated to find a job for them unless they are qualified for some kind of work. I say to them, "If you haven't trained yourself for any kind of work, I hardly know what kind of work to recommend to you." I suggest to them that they go back for some special training.

We all dream of the day when we will have specialized training centers, drug assistance and financial assistance and all these great things, but in Kansas we don't have them as yet. Nevertheless, being a native Wichitan, I know quite a few employers around town, and so far I have been able to help quite a few people find jobs if they were qualified.

I think that the more we are able to educate the public about the facts of epilepsy, especially as regards employment, and dependability, the more important it will become that the epileptic be qualified. It is true enough now, but as we educate the public to accept the epileptic and not discriminate against him he is going to have to prove himself even more qualified for job consideration.

Recently, a man came into my office looking for a job. His jaw muscles were throbbing -- I have never encountered a more uptight individual. I discovered that he had been released from a state mental hospital the day before to which his wife had had him committed for alcoholism. He said he began drinking because he could not find a job, or he could not hold a job when he found one.

We discussed whether or not he told his employer, when he applied for the job, that he was an epileptic. He said, "Last time I didn't. I had a job with a sign company. Everything was fine until I got up on a scaffold hanging a sign. The next thing I knew, I woke up in the hospital. Of course I lost my job because my employer then found out I was epileptic and wouldn't take me back."

I said, "You need to realize your limitations." He replied, "Look, mister, have you ever had a boy without milk, without food? Have you ever had to come home in the evening and tell your wife, 'No, I haven't found a job yet?' I'll do anything. I won't take a hand-out, but I'll take any kind of a job." Then I realized the size of the problem.

I knew a man who had hired epileptics before and I told my visitor to go directly to this man and say, "I'm subject to seizures. I'm an

epileptic." I advised him not to mince words, and said that the employer may or may not hire him, depending on whether he had an opening. The next day the man's wife called and said he was hired. His new boss had told told him that if he needed drugs or food or money for rent or gasoline, he would advance him fifty or sixty dollars on his first pay-check. It was a thrilling story of compassion.

How does one find employment for the young man who runs back home because he cannot hold a job? He has lost his family and falls back on his parents to take care of him yet he is twenty-eight years old. He has a problem other than epilepsy.

How does one reach and help a lovely young woman, who is so self-conscious because she has epilepsy that she cannot look one in the eye? All she can do is look down at the floor. She freely admits she is an epileptic. There are several things she can do, except control her own poise.

How does one help a middle-aged mother who says that even though she has minor seizures, she does not believe anyone else knows it, even her husband?

Or how does one help a person who calls in and says, "I have a friend who has terrible, terrible seizures, has had them for several years, and they keep getting worse. But the last time he went to a doctor, the doctor changed his medication and it didn't help. He is having seizures now during which he vomits blood, and he doesn't believe in doctors because his uncle doctored all his life and died from 'bleeding epilepsy'."

We do not give professional counseling. When these people have a medical problem we refer them to a group of qualified doctors for in many cases we find they have other problems much more serious than their epilepsy.

I want to tell you a little about what we have done in Kansas besides the usual things like trying to help people find jobs, referring them for medical consultation and handing out pamphlets.

Two weeks ago, after mailing out over five hundred invitations, we had an open house in our office where we entertained as many as we could possibly hold. The office is a medium-sized room with no partition, the secretary's desk on one side, and mine on the other.

One day two families came in with three small boys between the ages of three and five. Hanging around was a forty-seven year old World War II veteran who had the right side of his head practically blown away, and who had bone grafts and skin grafts which left him a little hard to look at. He had a very unnatural expression, especially in the right eye, where the eyelid had been grafted on. He wanted to help, wanted to know if there was something he could do or some way we could find him employment. Even though he takes medication, he has frequent, violent seizures. When these two families with the three little boys came in, I realized we had a "crisis", so to speak. I said, "Jim, you take charge of these boys; see if you can entertain them for a while." He took these three little boys,

who really wanted to entertain each other by making a lot of noise and running up and down the hall, and he kept them interested with nothing more than a set of crayons and some empty cardboard boxes for over an hour. He had them under control so that I could talk with the parents who were there for serious advice.

Jim was so happy when we complimented him on the way he took care of those little boys that he said, "That's what I want to do. I want to work with little epileptic children. I want to teach them how to run and play." Jim made a real contribution that afternoon because he was able to help the parents of those little boys in a real way.

At our open house, we made a concerted effort to talk to each one we suspected was an epileptic. One can usually tell. Our board members were on hand including Dr. Lauren K. Welch, a neurologist who is Chairman of our Advisory Board. We took the names and addresses of as many as we could, and let them know that we really intended to try to help them.

Since that time, we have had more calls, visits and letters in our office than in all of our previous two years' existence. These people are not asking for money; they are not asking for drugs; they are not asking for jobs. They areasking, "How can I help?" It was a revelation to me. We were wondering, "How can we go out and reach these people, to give them the kind of help we've got to offer?" As soon as we showed them that we wanted to help and offered some viable help, in a very small way, we found we had more people on our team wanting to help other epileptics than we could manage. We had to hire a secretary, just to manage our volunteer helpers.

A few days after our open house, a woman called to say, "Mr. Novak, I want you to know I have taken two baths this week all by myself." I replied, "That's wonderful." She said, "You must not remember me. I'm Mrs. _____, and I was there Sunday. Until I talked to some of the folks you had there, visiting with the epileptics, I wouldn't have had the confidence to do that. My husband wouldn't permit it, but now I know I can. How about talking to my husband and convincing him it's all right?"

Another woman called and said she used to be a reporter and writer. She is now unable to work. She said she would like to do something for us. We can certainly use a writer and typist -- we can keep her busy the rest of her life. Imagine the qualifications that this ex-reporter and writer offers us, free of charge. All we have to furnish is her paper and stencils. And we have since discovered that her brother is editor of a small newspaper about seventy-five miles away and he has agreed to publish occasional articles on epilepsy in his newspaper as well as seven other newspapers that he is associated with.

Miracles do happen. We could not have bought that kind of service; we just do not have the money. But through these personal contacts, the ball is rolling and snowballing. Once we wondered how we could get these things started; now we are wondering how we can keep up. The secret is education of the general public.

We are going to organize Kansas by establishing sub-chapters, sub-

agencies or whatever name one wants to call them. We already have had several citizens write in asking how such a thing could be done in their communities. So I don't think there is any question but that we will very soon begin to break out of the shell of stigma and darkness.

IMPLICATIONS FOR PARTICIPANTS

Discussion, Questions, Program Direction

Roger Meyer, M.D.
Regional Medical Coordinator
Social and Rehabilitation Services
Department of Health, Education and Welfare
Chicago, Illinois

The exciting aspect of today's discussion is its dimension and versatility -- things never learned or heard in pediatric training. The audience should be packed with medical students and allied health professionals. The rights of patients with seizures were still very marginal when I was in training and it was not so long ago that the chances for a normal life were seriously shattered and prejudiced.

Many of the people in medicine, too, were marginal in their ability to help people. As a previous speaker reported, even five or ten years ago the typical response of physicians to somebody with seizure disorders was to put him on medicine and say, "Come back if you have any problems." There were no laboratory tests, and no follow-up.

Most members of this audience today are not physicians, yet we focused heavily on the medical aspects. This may have been a little heavy for the rehabilitation counselors; nevertheless, the program committee deserves applause for putting the conference together.

Theme One of this workshop might be "Keep on Learning about Epilepsy." One fact that we have learned today is that 60% of the patients can become treatment-free and another 35% can become much more symptom-free than ever before. This is a tribute to the neurologists and their allies.

When I was in training, we received little training in epilepsy but were given a very detailed description of neurologic syndromes and biochemistry. Nobody ever told us how to handle the patient or his feelings, and this is terribly important. The Epilepsy Foundation is to be complimented for its excellent literature.

One of the important improvements in the past twenty years, from a practical point of view, has been the steady increase in federally funded programs which have been significantly increasing in the last decade -- fifteen-fold in terms of the actual dollar amount; the great majority of crippled children's programs include children with seizure disorders. The first financial grant by the Children's Bureau was made twenty-five years ago. Another important service is supplied by Vocational Rehabilitation; the practice of rehabilitation of these clients includes much practical support.

Usually the patient coming to the specialist has multiple handicaps and problems, requiring not only diagnosis and treatment, but counseling, vocational training, maintenance, transportation, job placement and follow-up. Most of us in the field do not coordinate things well enough. Theme Two emerging from this meeting is the importance of "Getting It All Together."

Industry and insurance have shown a great deal of interest in rehabilitation systems. I find that insurance agents and insurance representatives are impressed with the accomplishments of rehabilitation and rehabilitation counseling as an invaluable Resource System, whether epilepsy originates with trauma from an automobile accident or from congenital causes.

Epilepsy is a developmental disorder. As a pediatrician I find great significance in terms of the preventive implications, but nobody today has talked about prevention. I would to suggest that as you go away, you should think of all the opportunities you have, whether in state government or a private agency, to prevent epilepsy by reduction of trauma, better perinatal care, avoidance of infection and the many causes of seizures.

In recent years we have gained the technical knowledge to deal with some of the problems, through automobile seat belts, immunizations against measles, influenza and other great causes of seizures and other mental retardation problems, yet epidemics of epilepsy-producing disorders continue to plague mankind because we have not applied all our technology.

In my experience, one of the most serious hazards of an epileptic disorder is not the seizure but the associated emotional and social disturbances which develop as a consequence of mismanagement by the teachers, family, peers and friends. The establishment of a national program which is oriented to this aspect in children with developmental disability is critical.

Robert Q. Lewis noted once that maybe the questions are more important than the answers. Let me share with you some of my own questions arising from our discussion today.

My first group of questions is:

1. Have you developed your own helping capacity to the fullest?

2. You have many strengths in your neighborhood and state. What are they and where are they and how can you use them in your work?

3. How can you get the DD Council to do what it is supposed to do?

4. How can you get the Welfare Department to wake up out of its traditional lethargy?

5. How can you get the Health Department, professional societies and the medical societies to realize and rise to this potential?

My second group of questions is:

1. Have you got things together?

2. Once you awaken resources to your opportunities, what are you going to do with them?

3. We clinicians and administrators have got to organize and communicate better.

   How do we become better partners with the community?

4. Define the task you want people to get together on. How are you going to mobilize financial support?

5. One of the biggest challenges is putting money together.

   How many people in this room know what revenue sharing means and have tried to obtain that money for their programs?

My third question is:

How are you using the medium to "massage" your public?

My fourth question is:

What are the results?

1. How many people are in jobs, how many people have been contacted, how many pieces of literature have been sent out, and what has happened as a result?

   You should all begin to build in that direction.

2. How many children with seizures are in school where they should be, and how many are in special classes and out of the running?

3. Are the patients we reach finding our efforts helpful?

In the future we will be asked to be more accountable. The Professional Review Standards Organization is now a matter of law. If we spend public or private money, we must be accountable, and say, "What do we get for that money? How many people got better, or have found jobs?"

We have found that many of the children who had similar disorders were picked up not only very late, when it was obvious what they had, but were introduced very slowly into the mainstream of crippled children's programs and therapy, years after they were first detected; there is no excuse for delay in treatment and rehabilitation.

The final point I would like to make on closing relates to

consolidating your gains. Everyone here has made some important contribution to the field or he would not be attending this important workshop. How do you keep people working together closely, and once you've got them together and programmed, how do you map out the tasks for the next year? One of Mayor Daley's sayings is, "People can't get together because they don't get together." We have to keep people coming together and focusing on the issues and on what has to be done. One of the sad things today about professional life is that we haven't really dug down deep enough in our own resources to get together.

When I served as Director of the Children's Rehabilitation Center at the University of Virginia, I was stopped one evening by a four-year old patient who happened to have a seizure disorder. She was usually a quiet, ordinary girl, but this evening she blocked my way as I was hurrying home and said, "Dr. Meyer, have you done all you're supposed to do for us children today?" That question is one we should ponder on as we close here.

Have we done all we should?

Summary of Afternoon Session

Benjamin Boshes, M.D.
Chairman, Department of Neurology
Northwestern University Medical School
Chicago, Illinois

Let me in the next few minutes tell you what I heard this afternoon.

Dr. Gibbs' description of medicine and machines was an important contribution to th broad image. I would add one note of caution. Epilepsy is a disease, that is, a clinical disease. It is seen in people, and it is also seen in animals. The diagnosis is made on clinical grounds, on history, the observed seizure, and the findings. The electroencephalogram is important but not essential in making the diagnosis of epilepsy. It has added enormous knowledge and we can't begin to measure the impact of Hans Berger's contribution of 1929.

In 1943, I had the privilege of having the first brain wave machine in combat, in Italy. We had two of them, one in the hospital behind the lines and one in an ordnance truck we took up to the lines. I still have four hundred records taken of men right behind the lines where we distinguished withdrawal from true seizures. This is an important problem in the Army, because to be separated from the Service one had to either see the seizure or have electroencephalographic evidence. It must be remembered that it is not possible to have such a machine everywhere.

In 1971, the International League Against Epilepsy asked that several of us go to Africa to meet with some of the smaller nations where there were seizure problems. We were to meet in Uganda for a symposium. At that time there was a small revolution as is frequently the case, so the formal trip was cancelled; however, my wife and I made the trip on our own.

I had visited Makarere University before and I knew the chief of Neurology and Psychiatry, so I went there. Dr. Will German and his associate, Dr. Farrell, were gone that day. Using a Landrover type of vehicle, they had gone through a whole series of villages -- this was their day of epileptic clinics in Uganda -- and they traveled over two hundred miles over back roads into the villages to take care of people suffering from seizure disorders. They came back that night full of excitement and these were mature, neurological clinicians describing what they had seen and what they had done. Even in these small villages in Deep Ugaida, where one would expect to meet chiefly lions, leopards and elephants, there are people who have seizures.

A good clinician makes the diagnosis of seizure disorder by examination. While we use the EEG machine to help us, there is also a reverse side of the coin. If one hundred people are examined by EEG, several percent will have an aberrant brain wave pattern, although they have never had a seizure or a blackout. This was studied in the Air Corps by Dr. Donald Bennett, now Associate Professor of Neurology at the University of Utah. He followed a group of such men for eight or ten years and they did not develop what we call epilepsy.

We are violating the Bill of Rights of the Constitution if we say that because of his brain wave, a particular man is suffering from epilepsy. Immediately he is excluded from a job on the basis of a brain wave, when actually there has been no clinical evidence over the years. Does he have an inclination for seizure disorders? This remains to be proved.

I would point out to you that a diagnosis of epilepsy is based on history, the character of the repeated alteration of consciousness. The EEG frequently may show characteristic brain waves. Even 3-per-second spike and wave is a rare form in adults, associated with psychosis, not with seizures. The "computer" that sits on your shoulders is by far the best mechanism.

In the treatment of epilepsy in the modern era, Dr. Meyer has already alluded to the fact that total control has been achieved in 60%, perhaps even higher in some groups, and we are reaching the helping point in more than 90%. We have a great deal of therapy to offer. As I look back over forty years of experience in the field of neurology, I cannot think of anything more gratifying than the treatment of the patient with epilepsy. I now have the third generation and they are all still my friend. They come as a friend with problems, because somewhere along the line I was able to help one of them in the seizure state.

Dr. Gibbs described how we are beginning to get help through gas-liquid chromatography, which may be displaced by even more elaborate methods. We are learning more about how the drugs act, and Dr. Gibbs spoke to that. A great area of science is opening up there.

Ms. Lester spoke about community and professional education and this is an area of enormous importance. Every speaker has alluded to it. The great need is to be able to talk about the illness, to be able to understand it. It reminds me of the lovely words that Adlai Stevenson spoke about Eleanor Roosevelt when she died: 'She never complained about the darkness. She lit a candle." This is what we must get across in epilepsy.

Ms. Lester pointed out the need for doctors, for clinics, for agencies, for schools, and for community resources, to have a person or persons who can explain the illness, to help the people understand. She spoke of the success of the Cleveland Center, which is open seven days a week, and which gives individuals a window into which to look and receive an answer.

Ms. Lawless discussed the problem of epilepsy in the vocational area, and again, everyone who has worked with the person with epilepsy knows the impact here. She put together very well how much these services are universally needed. There must be a person, there must be agencies, who can interpret to the employer that when the employee is an individual who has seizures, the employer is still hiring a person with skills and abilities, and are these potential seizures a reason not to employ him?

Let me divert for just a moment. Last year, representatives of one of the large steel mills, one of the great corporations of this country, came to me with one of their men and said, "Please don't let him have another seizure." They had installed a forty million dollar machine which

produces bands of steel tape for wrapping steel or lumber. The band is extruded from a white hot ingot and put through the rollers, and as it comes through it is covered with the blue plastic which gives the blue color one sees on the trucks. The product varies from small bands to bands that will hold pillars.

For months they had tried to get this machine working, and no one could work it. Then along came this man, who was an electronics expert. He got up on the machine, the control panel of which is about a block long; he had to walk through the mechanism. These are enormous gears some fourteen feet across and the temperature is up in the thousands of degrees when the plastic is applied. Pretty soon they were turning out thousands of yards of rolled steel. One day as the man climbed to his post, he had a grand mal seizure. They studied him at one of the hospitals in Gary, gave him an EEG, put air in his brain, and so on, and they came to me and said, "Don't let him have another seizure. We want him back." Then the union stewards came and said, "You stop his seizures." In other words, industry was coming with an order, "Stop the seizures." Not, "Is this man safe?" but "Stop the seizures! We need him." So sometimes you get the reverse request. Could I put this man back on the machine? I had visions at the beginning that he would come out as a band, all blue and very dead. But, as in everything, there is a middle ground, and the employers must be informed of it. This bridge is exactly what Ms. Lawless referred to.

Mr. Novak reviewed their experiences in Kansas City, and I am sure any of you in any community could repeat what he pointed out. Certain things are needed; they should be available but they are not available yet. There must be a continuation of the education of the community, and this comes down to what Dr. Meyer pointed out -- the change in the scene. When I began my neurologic education, epilepsy was bromides plus phenobarbital. Mebarol came in 1932. There was no control of seizures. Epileptics were people who were discarded or hidden; there was nothing else to do for them. Now the scene is changed. Government as well as educational agencies have recognized that the person with epilepsy is a source of manpower.

Dr. Meyer pointed out what the Federal Government is doing, the input in terms of money, so that rehabilitation counseling, agency direct help, et cetera, is gradually evolving; however, it is not all there yet. Each six months when I am to make my report to the Foundation on liaison, Mr. Perlman or Miss Gandy sends me the bills that have come through the Congress, pointing out what has been going on. Dr. Meyer indicated the enormous change that has occurred on the scene, and there is more to come. That doesn't mean you can stop for one moment, and I think the five "commandments" he offered are good guidelines.

I found myself listening today very interestedly even though I have been through this many times. There is always something new. The most important ingredient that has been added to the problem is people who are skilled, people who understand, and people who are willing to work in this enormous task. This involves directly somewhere between two and four million patients, and indirectly about twenty million of concerned relatives. So your target is a large one, and I think your bullets are being shot in the right direction.

QUESTION

Member: I haven't heard any discussion so far about dope or drugs as to how they affect the epileptic. There are quite a number of articles on this at the present time, and I wonder if the chairman would elaborate on the subject before the break.

Chairman Boshes: Let me separate drugs from what you call dope; that is, heroin, morphine, codeine and some of the other substances that people become habituated to. Basically drugs are "downers" or "uppers", as the youngsters call them. Downers are the more dangerous as regards seizures. Notice that I am not using the word "epilepsy".

When an individual is on drugs, particularly the barbiturates, and to those may be added drugs like the meprobamates which are called Miltown, Equanil and others, and also alcohol, and he has been taking these drugs in larger or smaller amounts, particularly a heavy amount at bedtime, and suddenly ceases taking them, he goes into a state of hyperreaction. That hyperreaction not infrequently builds up to a seizure, so that in the Emergency Room of our hospitals in this Center, one of the most important reasons for an individual arriving in a seizure state is not epilepsy, but drug withdrawal. This is true across the country.

Curiously, and this relates to what Dr. Gibbs said, the electroencephalogram of such a person is normal; these seizures do not alter it. And interestingly, this type of seizure, no matter how often repeated, does not respond to Dilantin and has to be treated in an altogether different way. Now, this is not epilepsy. These are withdrawal seizures from intake and cessation of medication. This is so important it is recognized in industry and by the military who do not classify this problem as epilepsy. The regulations separate it out clearly.

The uppers, the amphetamines, Ritalin, drugs of that sort, ordinarily do not produce seizures. They evoke a state of hyperresponsivity of the nervous system to the point that frequently the circuitry of the brain becomes stretched beyond capacity and this organ decompensates and the individual breaks with reality. Not infrequently persons on massive doses of uppers come in with a psychotic state, usually with paranoid coloring.

Some of the psychedelic drugs, such as LSD and peyote, will produce hallucinatory episodes, but these are not seizure states. In actuality, there is no direct relationship between these drugs and epilepsy.

In certain forms of alcoholism, after many, many years where there are changes in the brain, we do see seizure states. These are associated with the pathological changes but this syndrome is becoming less frequent. Again, these are not epilepsies.

It is curious that there is such high specificity. We are entering into a new era of science, of micropharmacology or microchemistry of the brain that deals with this.

Opening Remarks

William Ferguson
Developmental Disabilities Consultant
Regional Services Administration
Social and Rehabilitation Services, Region VII
Kansas City, Missouri

We hope this will be the first portion of a two-part conference. Mr. Vogt, Dr. Olson and I have discussed the possibility of a second meeting which will also be sponsored by Regions V and VII in this bi-regional effort to get epilepsy more attention. There is a great need for more conferences of this type to inform both ourselves and others on all levels about epilepsy and its relationship to the Developmental Disabilities program. We don't know when the next conference will take place but we do hope that everyone here today will be present at the next one.

First on our program this morning is Ms. Marcile Perrin, who is Executive Director of the Nebraska Epilepsy League and also a member of the Developmental Disabilities National Advisory Council.

Developmental Disabilities -
National and Local Relationships

Marcile Perrin
Executive Director
Nebraska Epilepsy League
Epilepsy Foundation of America
Omaha, Nebraska

I welcome the opportunity to speak to you this morning about the relationship of the National Advisory Council to the State DD Councils, the regional staffs and the other concerned groups and individuals.

Six months ago, I could have said, "This is covered under developmental disabilities, and this is not." Now there are three bills* up before the Congress, the House bill, the Administration bill, and Senator Randolph's bill -- all tentative bills -- and nobody knows what is going to happen.

The original Developmental Disabilities Act expired at the end of June 1973, and it was extended for one year. In less than six weeks, we again face the same dilemma, because it will expire again. The National Council originally recommended an extension of the bill for five years. In these three legislative bills, one suggests extending it two years, another three years, and the Randolph bill suggests five years; no doubt the final bill will be a compromise. Various national groups, including the consortium of seventeen national health related voluntary organizations, are testifying, advising, and hopefully influencing the final results.

The Developmental Disabilities Act is one of the most significant pieces of federal legislation to be passed in recent years, and was obviously intended to be an ongoing program. How can effective long-range planning be done anywhere under the present short extensions of time and low level of funding?

Although the DD Act authorized the National Council, the Council was not established until July 1971. No members were appointed until October 1971, and the first meeting was held in January 1972, which is quite good for a federal council. Since then, the Council has met seven times, and the November 1972 meeting was held in conjunction with the National Conference of State Council Members and Staffs and State Administrative Agency Staffs. The meetings are open to the public, and records are maintained for inspection in Room 3062 of the Mary Switzer Memorial Building in Washington.

The February 1973 meeting was the first under the Federal Advisory Committee Act. This Act requires that each Federal Advisory Council have a charter which is subject to renewal every two years. Although we had been meeting for only a year and a half, our charter was due for renewal on July 1, 1973. Fortunately the charter was renewed or all appointments to the Council would have been void.

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* Comparative digest of these bills, page 95

The National Council is composed of twenty members appointed for four-year staggered terms. Ten of the original members have already rotated off, and five have been replaced; another five will leave on December 31 of this year.

A great variety of interests and professional skills are represented on the Council. They include consumers, state agency heads, voluntary agencies, universities, and other related professions. Five members are parents of disabled children.

The duties of the National Council are to advise the Secretary on regulations and determine the effectiveness of the programs authorized. The Council does not have planning authority. In the Randolph bill the word "Advisory" is eliminated from the title, and it would become a planning council, which in many ways seems more sensible. But at present, it advises only. The Secretary disposes.

In July 1972, when Elliot Richardson was Secretary, he asked the Council to advise him on extension of the DD Act. This advice was included in the Senate hearings. Some of the recommendations were as follows:

1. Extension for five years with progressive increments of money.

2. Level block match, rather than one year 75% matching. This past year it has been 70%. The block match to remain at 80%.

3. Elimination of specific matches for construction in poverty areas with substitution of state planned priority for poverty areas.

4. Minimum allotment to territories of $50,000.

   This is felt to be very important because some of the allotments originally made for places like Samoa and other territories were not enough to get the groups together.

5. Delegation of authority for approval of construction projects to the state instead of the regional office.

6. Consolidation of discretionary fund authorities with a broad base and assurance that a significant portion would be reserved for projects of national significance.

7. Inclusion of cost of land in definition of construction.

8. Elimination of specified 75% matching for the University Affiliated Facilities operational grants.

9. Modified allotment for bringing small states into sharing of appropriate increases.

10. Advance funding.

    This is very important as sometimes there is a waiting period of two or three months before states know whether projects already set up through their councils are going to be funded.

    In addition, in March of 1974, the Council recommended that states be required to put up public tax dollars as the non-federal share instead of counting only the non-profit agency or grantee's dollar as the non-federal match. This presented problems to some poverty groups who had used "in-kind" services as matching funds. If the states put up this money themselves and then get it back from the different projects, this contingency would be covered.

11. That DD legislation be separated from the omnibus health legislation and not be incorporated in the Public Health Act. In all three of these proposed bills it is a separate entity.

The members of the National Council are not a passive group. We continually ask why. We asked to be actively involved in the projects of National Significance. This has happened. There are now sub-committees on evaluation, the future of the UAF's, technical assistance to the state councils, and community alternatives and institutional reform. Dennis Haggerty, who is a member of N.A.C. and a lawyer, is monitoring the National Significance Project on "Law and the Handicapped" at Notre Dame University, and Dr. Boshes, our Chairman today, monitors a project on "Technical Assistance to the National Council on National Policy Development."

Last year, although a total of $44.5 million was appropriated in the President's budget for DD, only $21.7 million was allocated to the Part C or the formula grants to the states. The 10% set aside for projects of National Significance was also taken out of the $21.7 million, so approximately $20.3 million finally reached the states in the Part C formula grants. What happened to the rest of the money?

Nebraska's DD grant was around $150,000. This represents a drop in the bucket! At the present level of funding, what we have is a concept or an idea, and just enough money to provide the "glue" to get existing agencies to work together.

University Affiliated Facilities received $4.5 million for operations. They need twice as much to expand or develop research projects.

Another $18.5 million was allowed for discretionary project grants under various authorities. Most of these funds are dispensed through the

HEW regional offices and by the central office of the Division of Developmental Disabilities, for example, for the service projects for the DD under the authority of Section 4A1 of the Rehabilitation Act.

From the beginning, there has been much controversy about who the developmentally disabled are and what constitutes a substantial handicap. The major issue involving other neurological conditions has been eloquently spoken to by various national groups, and in some of the new bills other neurological conditions are still included; in others they are not.

The National Council has advised the Secretary that the definition of developmental disabilities should be revised to eliminate the ideological factors and focus on the most substantially handicapped, defining the target population based on objective characteristics. The new definition should be consistent with and preferable to the legal definitions which set forth eligibility criteria for services and payments to disabled people in other established federal programs. The following language would meet this criterion:

"Developmental disabilities mean a disability which:

1. is attributable to a medically determinable physical or mental impairment,

2. originates before the individual attains age eighteen and has continued or can be expected to continue indefinitely,

3. constitutes a severe handicap to substantial gainful activity."

Autism is now included in all three of the new bills. The Randolph bill specifies learning disabilities plus any other condition closely related to mental retardation as it refers to general intellectual functioning or impairment, unadaptive behavior or requiring treatment similar to that for the mentally retarded.

There is agreement that regardless of the legal definition, service eligibility should be based on similar service needs. This is a complex issue and it would be impossible to find a solution that would be satisfactory to everyone.

One benefit that has already evolved from the DD legislation is that the national organizations representing the three disorders originally named in the Act are now making real efforts to cooperate with each other. The national leadership of the Epilepsy Foundation of America, the National Association for Retarded Citizens, and the United Cerebral Palsy Association have held discussions to provide a basis for joint action in specified areas. They recommended closer communication between the three organizations, especially in matters concerning legislation; closer coordination at staff levels regarding planned activities concerning legislation; exchange of information regarding statistics, programs and progress in

research; coordination in development of appropriate public relations materials. Increased participation by both volunteers and staff in appropriate conferences, workshops or other meetings is encouraged.

A good example of public relations materials is the new pamphlet, "Facts and Figures on Epilepsy." It not only covers the cause of epilepsy, but goes on to mental retardation and then to cerebral palsy, showing that there are similar causes for all three disabilities.

The Developmental Disabilities bill includes Projects of National Significance which are really pilot projects to test or set up new programs. Based on recommendations from the President in 1971, from the National Council, from regional HEW offices and from the Governors' Advisory Councils in the states, the three major areas supported by Projects of National Significance are the advocacy projects, de-institutionalization and institutional reform (both child and legal), and technical assistance to the State Planning and Advisory Councils. Some of these projects were already in operation when the National Council was formed, and in time we were briefed on their progress.

Several activities promoted by the National Council and the Division of Developmental Disabilities have contributed to better communication among the states. The National Conference for State Councils is a good example. It provided a sounding board for representatives from all the states and territories to voice their ideas, their needs, and make suggestions for improvement.

Some inequities in funding are now being corrected, such as the $50,000 minimum for any territory.

As a member of the DD Technical Assistance Liaison Committee, I am involved with the project of technical assistance to state councils. Members of the audience on state DD councils may have used the assistance of this group. This project was established at the University of North Carolina under the direction of Dr. Donald Stedman to develop and deliver technical assistance and consultation to the state and territorial DD councils.

The project assists the councils in their tasks of program planning and evaluation, program management, information and data dissemination, and developmental disabilities educational activities. The project is administered through the central staff in North Carolina, and they have a National Advisory Board, a national talent bank, regional teams, liaison with federal agencies, the National Council, and other public and private organizations interested and related to the developmental disabilities program.

A needs assessment is conducted with each state DD council and its staff. This activity includes a tentative technical assistance agreement, which is then reviewed in the regional office and by the technical assistance staff. The assistance given is tailor-made to meet the particular needs of each state council. An expert from the talent bank can be brought in to provide any needed expertise. At any point, if the need of the

council is answered or changes, the contract can be terminated, a new one implemented, or if the state council feels there is no more need for technical assistance and they feel they can "go it alone," the contract is terminated and the whole process ends. But the state councils must express their needs openly in order to utilize this assistance to the best advantage.

To date, forty-five states have used the services of the technical assistance system, and the more sophisticated councils have negotiated several different kinds of contracts with them.

In June 1973, the chairmen and staff of the state DD councils were invited to meet with the National Advisory Council. About fifty people attended, representing nineteen states. They have continued to meet. They attend the open National Council meetings and are now formally organized and meet the day before the National Council meetings, staying on through the Council meeting. This is an excellent way to keep communications open between the central office staff, the National Council and the state DD council representatives. The National Council welcomes their help and input.

It must be stressed that although the National Council does advise the Secretary and we do have his ear -- Secretary Richardson was very receptive to suggestions and recommendations -- the locus of power remains at the citizen/consumer level. Congressmen respond to the needs and requests of their constituents, and the Council can only advise.

Many states are developing new and creative approaches to provide services for the developmentally disabled population, an example of which is Ohio's protective services case management system. Some of the most exciting and innovative projects on the national scene are being developed at the local level and I would like to tell you about one our agency is involved in in Nebraska.

In January 1971, when we formed an Ad Hoc DD Council in Nebraska, there was some resistance to the new concept of state and local agencies working together, although I personally felt it would add new dimensions to everyone's services. As time went on, more of the state DD council members accepted the idea, and in fiscal year 1974 the Nebraska state DD plan called for establishing information and referral systems in each of the health planning regions across the state. In Region 6 (the five counties in the immediate Omaha area, with one-third of the state's population), four agencies combined their efforts to identify the developmentally disabled population, locate the services available from area agencies, uncover duplications or gaps in services, and set up an information and referral system for the developmentally disabled population.

A comprehensive service directory is being developed and information being disseminated to the public through the various news media. The agencies involved are the Nebraska Easter Seal Society, United Cerebral Palsy of Omaha, Eastern Nebraska Community Office of Retardation, and the Nebraska Epilepsy League.

When representatives from all four agencies first met it was difficult

to believe they were all there to cooperate, but indeed they were, and it is working out. It has been an exciting and challenging project, so much so that we are now busy planning outreach, follow-along and expansion of the project, using the information gathered to provide new and better services for the developmentally disabled. There is a great opportunity to "latch on" or "lock into" existing services, many of them much more adequately funded than developmental disabilities, and the cost of a comprehensive program for the developmentally disabled child or adult then comes from many sources.

There is a clause in the original DD bill which says, "Do not duplicate services. Find an existing service and work it out together." This is what we have tried to do. We have had tremendous help from our state DD staff and from Bill Ferguson and the technical assistance team serving Region VII of HEW.

There is a built-in evaluation in these projects. We are reviewed by the state DD council and staff every quarter, and we also make our own evaluations. Each of the four agencies is accountable for the activities it has agreed to provide, and this is probably one of the criteria. We are responsible for the money that we received and for the services we said we would provide.

Several agencies are now in the talking stage about a pilot parents' project which would include all types of developmental disabilities.

I would like to close with an excerpt from the September 1973 National Spokesman, the monthly publication of the Epilepsy Foundation of America. It is from an article written by Jan DeMoors, a young woman from California who has a successful career despit an active seizure disorder. Miss DeMoor says:

> "When discouraged myself, I read the following quotation: 'No man is entitled to sit back and declare himself defeated. From the circumstances of his life, from his abilities, his insufficiencies, his courage and his fears, from the strength of his joy and the ache of his pain, he must weave the pattern and texture of a life fulfilled. If he refuses, he and all life everywhere will be defrauded.'"

DISCUSSION

Dr. Mayer: To add to your mention of the parents' group. We now have forty-five parents' organizations covering all the handicaps, with their own directory, annotated and cross-indexed by problem, all developed in the last five years. We have developed annual workshops. It is always a threadbare operation financially, but as a kind of power coalition it is unbeatable. We have passed legislation and acted as advisers to the Board of Education, and it is really effective.

People need to have patience and keep bringing all the handicapped groups together, the professionals have to learn

to be better partners with the parents.

Ms. Perrin: It is so true, and every area has its own problems and its own solutions that can be worked out to fit specific needs. The project I talked about is to help parents with, for instance, a child with epilepsy, relate to somebody who has handled the problem and is on top of it. There will be a central office and directory so that these families can be matched up.

Dr. Meyer: It is clear that services are rediscovered as parents become aware of what help they need.

Ms. Perrin: They have realized across the country that one of the great needs to make the DD program get off the ground was to provide this information. The trend, nationally, under the state formula grants, is not to fund some little project here or there that would be an extension of existing services, but to fund projects that produce services statewide. If a project doesn't have a broad impact, it probably won't be funded.

LEGISLATIVE BILLS FOR DEVELOPMENTAL DISABILITIES ACT

Item	H.R. 14215	Administration-Javits Bill S.3011	Randolph Bill S.3378		
1. Length of extension	2 yrs.	3 yrs.	5 yrs.		
2. Level of authorizations			75	76	77
a. States Formula	75-$50 million 76-$85 million	such sums as necessary	$40.0*	$55.0*	$70.0*
b. UAF New Construction	0	0	0	0	0
UAF Modernization	0	0	5.0	5.0	5.0
c. UAF Operation	75-$12 million 76-$15 million	such sums as necessary	20.0	20.0	20.0
d. Evaluation	0	0	1.0	1.0	1.0
e. Bill of Rights	0	0	"Such sums as are ne make grants..." (7		
3. Consolidate authorizations for project grants	Project grants 75-$15 million 76-$15 million	0	Project grants $15.0	$17.5	$20.0
4. Minimum allotment for territories	$50,000	$50,000	no change from P.L		
5. Delegate to states review of construction projects	Yes - State Plan assurance	Yes - State Plan assurance			no

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LEGISLATIVE BILLS FOR DEVELOPMENTAL DISABILITIES ACT

	H.R. 14215	Administration-Javits Bill S.3011	Randolph Bill S.3378				
sion	2 yrs.	3 yrs.	5 yrs.				
izations							Million*
la	75-$50 million 76-$85 million	such sums as necessary	75 $40.0*	76 $55.0*	77 $70.0*	78 $85.0*	79 $100.0*
truction	0	0	0	0	0	0	0
ation	0	0	5.0	5.0	5.0	5.0	5.0
n	75-$12 million 76-$15 million	such sums as necessary	20.0	20.0	20.0	20.0	20.0
	0	0	1.0	1.0	1.0	1.0	1.0
ts	0	0	"Such sums as are necessary... to make grants..." (75% Federal)				
horizations rants	Project grants 75-$15 million 76-$15 million	0	Project grants authorized: $15.0	$17.5	$20.0	$22.5	$25.0
nt es	$50,000	$50,000	no change from P.L. 91-517				
tes review on projects	Yes - State Plan assurance	Yes - State Plan assurance	no				

Item	H.R. 14215	Administration-Javits Bill S.3011	Randolph Bill S.3378
6. Definition of Developmental Disabilities	change to include autism	change to include autism	includes autism and lities plus "any oth closely related to m as it refers to gene functioning or impai behavior or to requi similar to "...MR... before age 18, lasts which constitutes a to such individual's function normally in
7. Include cost of land in construction	no	yes	no
8. Earmark for de-institutionalization	75-10% of Formula grant 76-30% of Formula grant	State Plan assurances requiring use of some funds for this and included in purpose clause	Title II, Part A set standards. Part B p Federal matching gra lic facilities up to the basis of a State 5 years, institution standards, it will b receive payments dir under any Federal la necessary are author
9. Eliminate 75% limit on Federal Match for UAF grants	yes	no	no

em	H.R. 14215	Administration-Javits Bill S.3011	Randolph Bill S.3378
Develop-ilities	change to include autism	change to include autism	includes autism and learning disabilities plus "any other condition... closely related to mental retardation as it refers to general intellectual functioning or impairment in adaptive behavior or to require treatment similar to "...MR... which began before age 18, lasts a long time and which constitutes a severe handicap to such individual's ability to function normally in society.
f land ion	no	yes	no
-institu-	75-10% of Formula grant 76-30% of Formula grant	State Plan assurances requiring use of some funds for this and included in purpose clause	Title II, Part A sets forth (JCAH) standards. Part B provides 75% Federal matching grants to bring public facilities up to standards, on the basis of a State Plan. If, after 5 years, institution does not meet standards, it will be ineligible "to receive payments directly or indirectly under any Federal law." Such sums as necessary are authorized.
imit tch for	yes	no	no

Item	H.R. 14215	Administration-Javits Bill S.3011	Randolph Bi S.3378
10. Funding for National Significance Projects	minimum of 30% of project grant funds; i.e., $4.5 million, leaving $10.5 million for project grants	as present law up to 10% of Formula grant funds	up to 10% of Formu appropriation
11. Regulation	--	--	general regulation after enactment.
12. State Plan Submission	--	--	180 days after ena
13. Federal share	75% for FY '75 and FY '76 for all activities	70% - FY '75 60% - FY '76 50% - FY '77 for all activities	70% - non-poverty 90% - poverty area 66-2/3% - construc
14. State Council			"Advisory" removed g.ven great author over implementatio agencies; shall pr Plan and monitor a implementation, ap Governor.

	H.R. 14215	Administration-Javits Bill S.3011	Randolph Bill S.3378
onal rojects	minimum of 30% of project grant funds; i.e., $4.5 million, leaving $10.5 million for project grants	as present law up to 10% of Formula grant funds	up to 10% of Formula grant appropriation
	--	--	general regulations due 60 days after enactment.
ssion	--	--	180 days after enactment.
	75% for FY '75 and FY '76 for all activities	70% - FY '75 60% - FY '76 50% - FY '77 for all activities	70% - non-poverty areas. 90% - poverty areas 66-2/3% - construction
			"Advisory" removed from name; given great authority and control over implementation by State agencies; shall prepare the State Plan and monitor and evaluate its implementation, appointed by Governor.

Item	H.R. 14215	Administration-Javits Bill S.3011	Randolph Bi S.3378
15. Evaluation			Requires Secretary Congress 18 months on evaluation syst shall implement an system compatible w one. Must cover s on consumers, State benefit ratio.
16. Study	Secretary shall determine: (1) other neurological conditions to be included in programs and within 6 months after enactment report to Congress what conditions are and are not and reasons for each decision. To be reviewed annually. (2) Secretary contract for independent study to determine if the definition is appropriate, if not what and reasons for inclusion or exclusion; and adequacy of services under other Federal program to those not included within the definition. Report due to Congress 18 months after date of appropriation for study.		

H.R. 14215	Administration-Javits Bill S.3011	Randolph Bill S.3378
		Requires Secretary to report to Congress 18 months after enactment on evaluation system. Then States shall implement an evaluation system compatible with the national one. Must cover services, effects on consumers, State impact and cost-benefit ratio.
Secretary shall determine: (1) other neurological conditions to be included in programs and within 6 months after enactment report to Congress what conditions are and are not and reasons for each decision. To be reviewed annually. (2) Secretary contract for independent study to determine if the definition is appropriate, if not what and reasons for inclusion or exclusion; and adequacy of services under other Federal program to those not included within the definition. Report due to Congress 18 months after date of appropriation for study.		

Item	H.R. 14215	Administration-Javits Bill S.3011	Randolph S.33
17. National Council on Developmental Disabilities	--	--	Effective July 1, is eliminated fro Members included and 15 non-Federa which at least fi sumers. Meet at year -- its initi 90 days after ena to Secretary and on the developmen of the program.

	H.R. 14215	Administration-Javits Bill S.3011	Randolph Bill S.3378
on	--	--	Effective July 1, 1975, "Advisory" is eliminated from the title. Members included six DHEW officials and 15 non-Federal employees of which at least five shall be consumers. Meet at least twice a year -- its initial meeting within 90 days after enactment. Report to Secretary and Congress annually on the development and evaluations of the program.

Social Services for the Epileptic: Breaking Barriers

Phillip Rennick, Ph.D.
LaFayette Clinic
Detroit, Michigan

I am Chief Psychologist at the LaFayette Clinic where I have worked primarily with epileptic patients. I also work at the Epilepsy Center of Michigan as the Director of Psychosocial Research, and represent the Center on the State Council of Michigan from the consumer point of view.

I thought I might take this opportunity to explain to this group, many of whom may not have a great deal of knowledge about epilepsy, what some of the psychological and social service requirements are for these patients.

You heard yesterday that epilepsy is a disorder of the brain; however, it is not always associated with brain damage. Sometimes people with epilepsy have seizures but never know the intellectual impairment which is often a consequence of brain damage. In about half the cases, epilepsy can be seen as a disruption on a temporary basis of the functioning of an otherwise good brain, whilst in the other half of the cases, it is connected with more or less severe impairment of other brain functions, such as intelligence, memory, capacity to pay attention, language skills, and similar activities. In the latter instances, the people with epilepsy do need services similar to those for the mentally retarded or even those with cerebral palsy.

It must also be remembered that sometimes epilepsy affects primarily those parts of the brain which have to do with feelings, drives, emotions, and aspects of personality. The person with epilepsy may have a fundamental biological deficit in his capacity to organize these emotions and drives. That, together with the fact that having epilepsy in our society creates around the individual an environment which is highly conducive to the development of emotional problems, suggests that there ought to be a fair amount of psychological disturbance in the person with epilepsy, independent of any intellectual impairment. The evidence is that this is so.

There is no such a thing as an "epileptic personality"; there is not that much commonality of symptoms. We have found that each person with epilepsy is an absolutely individual case and has to be looked at carefully to see how the disorder manifests itself in the particular instance, including the psychosocial circumstances of his life. When this is done, and appropriate early intervention occurs, many problems are reversible. One must therefore not be surprised if the person with epilepsy has requirements that differ from those of retardates.

I strongly urge that the Developmental Disabilities Administration be aware that the epileptic person generally has no other advocates in state government. Developmental Disability may be the hope for the development of services which can alleviate or even prevent the psychosocial concomitants of this disorder as well.

I will next outline what are some specific services in the psychosocial area that are needed when the diagnosis of epilepsy occurs, and then discuss how some of these services might be established.

When a diagnosis of epilepsy is made there should be an evaluation of the psychosocial circumstances of that individual. One should get rid of the notion, once and for all, that epilepsy is a purely medical disorder treated very simply by medicine, even though we may put out this picture for the public to reduce the prejudices against the person with epilepsy.

Public statements concentrate on the view that, other things being eqral, a person with epilepsy should be treated like anyone else with a simple physical disorder, but we ourselves are a little schizophrenic about it. We have to put it in our statements to combat the terrible prejudices and stigma that exist, but when we are talking about program support and real needs, we have to be realistic. We have found that the diagnosis of epilepsy in the first place is almost always a catastrophe, not only for the individual but for the family and that appropriate intervention at an early stage based on realistic evaluation of the characteristics of that individual can head off the long-term consequences of that catastrophe.

That is another place where epilepsy differs from the case of mental retardation. It is possible to prevent many of the bad personal-social consequences of having epilepsy much more thoroughly than in the case of a mentally retarded child, because one knows that such a child will have to live for a long time in the family circumstance with a disorder which can be alleviated but not really modified to any great degree.

Too often, a person with epilepsy can have his seizures controlled but still have terrible psychosocial consequences. You are probably aware of the kind of superstitious dread with which epilepsy is regarded in some families. We have many case histories in Michigan where on talking to the family we discover that they think their child with epilepsy is supernaturally affected; that the thing is a consequence of some evil act the parents did once in their lives, or some other retribution. They have a kind of magical, superstitious awe of the disorder. They regard the visitation by an awful divinity as a cross they have to bear, and they are not sure they should even take any action to make the child better because they think it is something they are supposed to put up with. The reflex, therefore, is to hide it from the community, even to the point where they do not try to go out and get the services that are necessary.

Obviously the child growing up with his family feeling that way about him is going to have a very distorted development, and this is a case where decent intervention with the family to combat this superstitious, destructive nonsense is so important, by explaining that it is a simple medical disorder of the brain, that we understand a fair amount of its ideology and treatments and that it is no visitation from an awful divinity. This kind of thing can be a tremendous help in the natural development of the child, but we have found that it is not easy to do. It takes a great deal of patient work and family treatment in many cases to get the idea across.

In addition to the evaluation of the family attitude to the disorder, the individual himself needs a good psychological workup. In many cases the individual with epilepsy experiences some tremendous traumas as soon as it occurs. His school friends start laughing at him, his family starts rejecting him or treating him in a very inappropriate way and these have consequences within the individual. We have, therefore, to emphasize an assessment of the emotions, conflicts, and feelings (the personality side) of the individual, in order to understand how much work has to be done to habilitate him toward a more normal development.

In addition, one has to do the usual psychological assessment of the intellectual endowment of the individual, and find out what his aptitudes are. There is one special thing that has to be done in the case of epilepsy that not everybody knows about. There should be an evaluation of the psychological deficits in a given individual with epilepsy, asking whether or not they represent some of the effects of brain damage, because this is often an important factor in diagnosing and treating the person with epilepsy. Is it one of the ideopathic epilepsies with no consequences of or no association with an organic brain damage syndrome, or is it one which is representative of a symptom of another neurological disorder which might lead to other symptoms of brain disorder.

Over the past years specialized neuropsychological tests have been developed, which will answer this question. We do not know yet how well these tests predict success in school or other practical matters but they do contribute to the diagnosis of "organic or non-organic," as the basis of the epilepsy. Many major medical centers have neuropsychology laboratories where a full comprehensive neuropsychological workup can be done; there are also a few "quick and dirty" psychological tests of brain damage which can do more harm than good and should be avoided.

The diagnosis of brain damage as well as epilepsy can do more harm to the afflicted child than good, but it depends on the circumstances. For example, in some states even to this day, a child with perceptual problems, or motor coordination problems, cannot get into special classes or remedial work programs for amelioration of these problems unless he is labeled by a physician as brain damaged. In a large number of cases the neurologist does not find anything really concrete and depends heavily on what the psychologist says. In those cases where the "diagnosis" might be helpful in terms of what programs are available one may have to use it. On the other hand, one must be aware that in regular classes, teachers think it is a waste of time to work with someone who is "brain-damaged."

One of the services that is necessary as soon as possible after evaluation is what I would call problem finding. We have to set up systems for making the diagnosing physician aware of the psychosocial consequences of the disorder, and have some place to which he can refer his patient for a good look at that side of the problem.

There is an old tradition among neurologists of total case management, but in many cases that is one of the barriers to be broken; they do not have time for total case management any more. We have a distinguished neurologist in Michigan, in one of the medium-size cities, who manages epilepsy as a specialty, and for years he tried to do total management. When his wife had more time on her hands after the children grew up he

took her into his office as a kind of counselor. He discovered after the first few months that the patients to whom he had so carefully explained the disorder and its consequences had totally forgotten what he had told them, or had misunderstood. It became one of his wife's responsibilities to go over and over and over again the basic facts of the disorder with the patient, a process which the neurologist himself did not have time to do.

We have found that if one can get early intervention on the psychosocial side, one can help the patient so very much; therefore, one needs some kind of ongoing relationship between physicians and mental health workers to ensure provision of psychosocial services at the time when they can do the most good.

Once the evaluation is made and it is clear there are problems in the family and in the individual, one must set up a system for counseling, follow-along, or referral for patients with epilepsy. Again, we have discovered in Michigan that this really works best when we have specialists who have at least some additional training in epilepsy. What we do, for example, in the Epilepsy Center of Michigan is to take trained counselors who are working out in various cities in Michigan and bring them into the Epilepsy Center for three or four days of intensive, workshop training in the basic facts about epilepsy, facts which they generally do not know because they were not made available to them in their previous training, and then monitor their work with patients with epilepsy after they go back into the field. We reimburse their agencies for some of the hours they spend with their clients with epilepsy, and in return we get reports on what their caseloads are like, and they get a chance to offer feedback to the counselors.

We have found that ignorance among mental health professionals is quite profound and can have serious consequences. In fact, this is one of the barriers that must be broken. Most physicians know that the average social worker, psychologist, educational specialist or rehabilitationist person to whom he would refer his patients does not know the facts about epilepsy but nevertheless will make authoritarian pronouncements about the condition which might totally confuse the client and sabotage rather than assist the physician's treatment of the problem. We have to take strong educational measures to make sure that this does not happen if the physicians are ever to make such referral with confidence.

Two of the specialties developing within the mental health profession which may be easily applied to epilepsy are family therapy and group therapy. We find that treating the family as a whole unit around the client's disorder and its impact on the family, with everybody finally having a chance to really talk it over with a specialist present, has done very quick work in the way of rehabilitation, so that the individual with epilepsy gets better acceptance in the family setting, and the family members in turn feel they know how to go about helping. We have to depend on the family because there just is not enough mental health manpower for each client to be helped only outside the family.

Group therapy with groups of epilepsy patients has proved to be very good. We found that some of it goes on informally. We have set up

volunteer epilepsy organizations throughout the State of Michigan in various communities and one of the real functions of these organizations is to provide a kind of group process which is essentially therapeutic for parents or individuals with epilepsy. There is nothing like knowing that somebody else has just as bad a problem to help a patient or a family feel better about it.

A final kind of service that is necessary and useful in the case of epilepsy is the information/referral service of the type Ms. Perrin established. At the Epilepsy Center we handle about thirteen thousand pieces of mail just by way of information and referral. Somebody writes to the EFA who forwards it to us in Detroit, or a person writes to us directly. We send out brochures, some of which are the new, very good ones from EFA, and other packets of information, so that they get a big, thick set of materials to read. Furthermore, we try to set up referral networks throughout the state so that the person with epilepsy knows somebody in his area to whom he can talk about the disorder and its psychosocial consequences.

All of these, psychosocial evaluation, counseling, re-explaining, family and group therapy, are what I think are necessary for persons with epilepsy in addition to their medical treatment.

DISCUSSION

Ms. Perrin: Has Michigan recently established a GLC? Is it free?

Dr. Rennick: This was part of the leadership role the Epilepsy Center has long played in Michigan. Twenty-five years ago we had a portable EEG machine going around in a trailer van for better diagnosis. We put in a proposal for support of a GLC machine for serum scan to the state DDSA and pointed out that there were other states which had supported this kind of service through DDSA funds. They fought it, because the DDSA councils are dominated by people interested in treating children with mental retardation, and they did not see how a $30,000 grant to buy some machinery and hire a specialist to run it was going to help many retardates. We finally had to demonstrate to them that we had a serious interest in working in cooperation with the State Home and Training Schools, many of which have a large percentage of their populations with seizure disorders. On that basis we got it through.

Ms. Perrin: We need this in Nebraska, because I know that a great number of children in the state institutions, and some in the community facilities, are so overmedicated, or they have been on one medication for many, many years and they are probably toxic on it.

Dr. Rennick: One of the selling points we were able to get across was that there are commercial laboratories which will do these serum anti-convulsant levels using a GLC, but we have found that unless they are tooled up to do them on a specialized basis

the results are totally unrealiable. It is a very complicated gadget and can go wrong in many ways.

Member: Would you describe who makes up the Evaluation team at the Epilepsy Center of Michigan and then describe the basic function of that team member?

Dr. Rennick: The people at the Epilepsy Center have always believed that these patients needed psychosocial services of various kinds so they set up a multidisciplinary evaluation scheme which has been going on for about twenty-five years. It is done by a team consisting of a neurologist, a social worker, a psychologist, and often a psychiatrist. The social worker takes a detailed social, family and epilepsy history, and is the one who does the hard work with the family to try to uncover when the seizures started, what they looked like when they started, and what the previous treatment was, saving the neurologist a lot of time. The psychologist evaluates both the intellectual and personality state of the patient. Frequently, if the client is referred from another agency, we will have the final conference with all these people on the team together with the specialist from the other agency who may have to deal with the patient. But the basic workup is always neurological, psychological and social service.

As part of the neurological examination, we always include an EEG, which may be repeated two or three times, and the usual clinical/laboratory workup of blood, urine analysis, and other tests. Also we routinely do serum scans for anti-convulsant medications because frequently the clients we get are the kind of tough cases that are sent as much for a medical workup as anything else, and they have been on various kinds of anti-convulsant regimens before they reach us.

This particular workup is strictly a one-time diagnostic procedure. The next step is twofold: one, we try to interpret the results to the patient and his family, or the family alone, whichever is appropriate, and two, we try to give the referring physician back as complete a picture as possible of all the needs of the client, including our medical estimate as to what might be a better anti-convulsant regime to start him on, and especially the psychosocial recommendations.

We are very cautious about taking patients away from our referring physicians so we really do not have much ongoing medical treatment in the Epilepsy Center. However, the LaFayette Clinic, which is a state hospital for research and training in mental health disciplines, has turned its neurology ward into essentially an epilepsy ward, thanks to the efforts of Dr. Ernst Rodine, the Chief of Neurology, who is also Medical Director of the Epilepsy Center of Michigan. We do offer there a lot of medical treatment, both in- and out-patient, through the LaFayette Clinic. Mental health hospital systems are generally given the responsibility for dealing with epilepsy but they really do not have any way of

doing it now that they have closed down all the epilepsy hospitals.

Member: Is that service free or is it charged for?

Dr. Rennick: The Epilepsy Center is mainly supported by Torch Drive funds. In the State of Michigan, the Detroit United Fund contributes about half, and the United Way of Michigan contributes the other half; we have services on a sliding scale. The Torch Drive fund-raisers havefelt they have reached the limit in what they could get for their agencies and have been interested in our ability to obtain third-party payments wherever possible; every year we have been increasing the amount of insurance payments for these services.

Member: In addition to the team members, you could have a Nurse Clinician, and she is a very valuable person, because aside from taking the detailed history, she also does some examination.

Dr. Rennick: In Michigan the Nurse Clinician can not only diagnose but provide some treatment as a kind of doctor's aide. We do not have one like that in the Center, but we have just hired a nurse to help us with the comprehensive epilepsy survey we are going to undertake in the Detroit area and we do not know what she will grow into. These are nurses with specialized training at the master's level and they certainly could be very key people.

Member: Are you associated in any way with the University Affiliated Facilities Program?

Dr. Rennick: The LaFayette Clinic staff all have at least adjunct appointments at Wayne State University. We are probably about to be absorbed entirely by the University because of a fear that the Mental Health Department in Michigan is not going to support research and training efforts.

The Epilepsy Center itself is trying to maintain its independence as clearly as it possibly can but if we grow very much larger we will probably have to affiliate more administratively. We have all kinds of trainees from the University coming through, we have a library and research facility, and various training programs in social service, psychology, and neurology, and the professional staff are generally accredited academically for teaching purposes.

Ms. Perrin: I don't think there is a UAF, per se, right there.

Dr. Rennick: We do not have anything like that in DDSA. In Ann Arbor, there is the Institute for the Study of Mental Retardation and Other Related Disabilities which sometimes thinks of itself as being involved in epilepsy, but although their Director, Dr. Cruikshank, is a member of the DD Council I do

not think they are getting a lot of extra money. In Michigan most of that money goes to projects organized by the Association for Retarded Children.

Member: Have the developing associations that you mentioned or the group therapy programs created any problems with the local physician and individual patient relationship?

Dr. Rennick: There is certainly always the chance that they might and they has to be worked out very carefully. There is still no doubt that the physician usually feels he is the one who must supervise the services that are offered. If something goes wrong, the physician can get justifiably frustrated if he does not know a lot about it because he is not getting reports from other treating people. He is going to have the idea that it is the treatment at fault and not the patient's problems. We, therefore, try to coordinate, and cooperate, as much as we can to alleviate and obviate the problem. It depends on one's reputation; if the physicians have confidence in the group it will be all right. The thing to do is to get the physicians and other professionals in on the board and to the meetings so that they feel they know what is going on and can give some advice.

I would like to talk a little about some of the problems in getting these services for patients. There are many roads to take, depending on what is already existing in any given community. Many of the large city children's hospitals have seizure clinics, but they are not often a very good model of psychosocial service delivery systems. What generally happens in those clinics is that the patients come back every six months or so, and a very busy physician who is seeing seventy-five patients in a morning has barely time to ask what medication the patient is taking, how it is working, and present him with another prescription. That is really not handling the problem very well.

We have been slowly trying, by demonstration grants and research proposals, to augment the staffs of these clinics with social workers and psychologists who can help with problems as necessary and even take the time to ask whether there is one. Epilepsy is such a hidden disease that not only do the patient and family not want to reveal that the person has it but they do not even want to find out what is necessary to get the help they might need. If one has services to offer, one has to make it clear that the invitation is open. Once under way, the services are used, and generally create an increased demand for them.

It would probably be rare that the model developed in Michigan for specialized services within a state mental hospital would be copied. We have large populations classed with epilepsy in the State Home and Training Schools for the retarded. A few years ago the last hospital designed for epilepsy switched to a State Home and Training School. It had been a State

Dr. Rennick: (cont.) Hospital where a physician could commit patients with intractable seizures and provide a residence needed to care for those patients' seizures in the worst cases. But what happened over the years was that the client population there began to be more and more made up of those who were adaptably impaired as well as having seizures. So in 1968, with 90% of the patients being quite retarded they decided they had better de-emphasize the epilepsy part. As it turns out, their patient population now is 100% retarded but 85% with epilepsy, which is still a heavy load.

State Home and Training Schools and the State Mental Health Hospitals offer much promise, because with their specialization there is nothing to opening up an out-patient clinic for helping the epileptic patients in the community that needs good Mental Health services. Finally, the current emphasis on community-based programs, which is taking shape in all the State Mental Health systems, must be made to work for the good of epilepsy patients as well as mental patients or emotionally disturbed children.

Member: Do the patients with "normal functioning and intelligence" have any hesitancy about coming to a facility which is in effect a retardation facility?

Dr. Rennick: They do, and they also have hesitancy about coming to LaFayette Clinic because it is a psychiatric hospital. We have to change the names of these places; in some cases they are now called "human development centers." It would be better to spread the notion that epilepsy is a disorder that can be talked about and get specialized clinics for it.

Ms. Perrin: But your group is not housed actually within the LaFayette Clinic?

Dr. Rennick: The Epilepsy Center of Michigan is in a separate facility, but the LaFayette Clinic has a specialized clinic within it; they work together. We recently got the Children's Hospital of Michigan's Seizure Clinic and Neurology Clinic for children to join us under a three-way agreement, and this affiliation has added to our ability to attract one of these planning grants for comprehensive epilepsy services.

Member: Are the seizure patients seen as part of the whole neurology group?

Dr. Rennick: We have a twenty-bed in-patient neurology service at the LaFayette Clinic, and at any given time eighteen of them are probably filled with patients with epilepsy. Psychiatric residents rotate through this service. Epilepsy offers so many opportunities for psychiatric study as the patients have so many associated emotional problems, either primarily as a direct manifestation of the disorder, or secondarily because of the effect that epilepsy has on the family and on the social development.

Dr. Rennick: (cont.) One of the other possibilities that is being overlooked is Community Mental Health. In most states, services to patients with epilepsy come under a Mental Health Act, and the new Community Mental Health Centers have a responsibility for dealing with patients with epilepsy. We are just beginning to explore that in Michigan. With federal insurance and other third-party payments coming, nearly every client with a mental health problem is going to get services paid for by a non-state source, so the State Mental Health systems may well shut down almost all their facilities, except for the very long-term ones, and turn the whole thing over to Community Health Centers to run on a community level with third-party payments.

One of the things that can be done, and we are seeing it at Grand Rapids, is that a volunteer organization, such as a Chapter of the State Epilepsy League, can begin to provide some services. This is, to some degree, copying the model of the Association for Retarded Children, where they started their own day schools, workshops, and halfway houses. They can serve not only as advocates but actually band together to help in some of these services and often do some fund-raising to hire specialists to provide things like diagnosis and specialized treatment.

Just recently in Michigan, the local Grand Rapids association acquired a local grant to hire a full-time Executive Director, and with the recognition this brought, they became an official Chapter of the Epilepsy Center of Michigan. They then put in for a DD grant for longer-term support of the Director's salary and for an assistant; they received that grant too. So these voluntary organizations can really grow if they just have some really active, concerned parents, spouses, or even people with epilepsy themselves who have the talent and drive. I would say that in the Epilepsy Center of Michigan our best board members are those who have epilepsy and are dealing with it. We do not seem to have in epilepsy a situation where we successfully treat the child of one of the rich American families which then starts donating large sums of money.

Ms. Perrin: Another good thing would be if you could only get some prominent person to support it. Beverly Sills has two handicapped children and one of them has seizures but she will not appear on TV, except on behalf of birth defects.

Dr. Rennick: A few celebrities who have epilepsy are coming out themselves but no one with children who have it. It is the most unpopular disease from the point of view of foundation support.

I would like to close with some comments about some "conflicts" between parents of children with mental retardation and the epilepsy people.

Dr. Rennick: (cont.) The original DDSA legislation said something to the effect that it was to provide services and seed money for projects involving mentally retarded, cerebral palsy, epilepsy and other neurological disorders requiring services similar to those provided for the mentally retarded. This has universally been interpreted by those on the Michigan Council who advocate services for the retarded to mean that both cerebral palsy and epilepsy are under it only insofar as they need services comparable to those for the retarded.

Ms. Perrin: That is not a national view.

Dr. Rennick: I know, and it is not the view of the staff of the State Council, but as far as the Council's advice and consent in regard to state programs is concerned, it always comes out that anything for cerebral palsy and epilepsy are all right, provided the services are needed for the retarded. We have to get the point across that epileptic individuals need different kinds of services and that they should be provided for under this Act. They particularly need case finding and rapid intervention to head off serious consequences, which is money-saving from the point of view of society, because the need for long-term care and continued hospitalization can often be eliminated. A strong case must be made that services that focus on symptoms related to epilepsy alone, including the psychosocial consequences, can and should be funded through the Developmental Disabilities projects.

Member: I disagree that case finding and early intervention are different kinds of services, because I would say they are true for cerebral palsy and mental retardation.

Dr. Rennick: But it is case finding in terms of planning for special education, rehabilitation and services of that type. In the case of a person with epilepsy, who has not got those intellectual or physical handicaps, there is still a critical need for specialized, often brief, help for his adjustment problems. Otherwise, a wrong start is made and can make the individual suffer a lifetime handicap.

Ms. Perrin: I think one of the big problems is because the DD Act is an outgrowth of the original MR legislation and it is very difficult for them to let go of it. Also at the state level the MR programs are so much better established, so much better funded, and the federal agencies in the state that are also on the DD Councils at the state level are getting so much of their money from this already established service. It is very hard to change.

Dr. Rennick: It is very, very hard, but it has to be done. One of the differences is that about ten or twelve years ago the Associations for Retarded Children began to really drive, and to admit that their children had the disorder, that it was a problem to be taken care of, and they began demanding services. That has not happened often in the case of epilepsy, because

the parents want to conceal it as far as possible.

Ms. Perrin: Once you get in there and have early identification and prevent these future problems, you destroy the group, and you do not have the continuing support that you get with MR.

Dr. Rennick: As soon as the problem is taken care of the whole family goes back into hiding. That is a point in our favor if we handle it right, because this means the DD Councils have to recognize that they will not get the same kind of advocacy from clients with epilepsy and their families as from the other groups.

Ms. Perrin: It is difficult to form a parents' group and keep it going in epilepsy, because you have to form a new one every year.

Dr. Rennick: But it is not completely true that all clients with epilepsy disappear as soon as they get seizures under control. Very frequently the seizures recur either because the patients stop taking medication or because the medication itself does not work. The studies Dr. Rodine did in Michigan showed that in five-year followups, we get about a 20% ratio of total freedom from seizures, which is a lot different from the 80% total freedom one hears about for six months or a year.

Ms. Perrin: In the meantime, the parents say, "Take us off your list for a while."

Dr. Rennick: Yes. Perhaps the new GLC serum levels measurements will help in the continuing management of this chronic disorder, because they really ensure that the clients take their medicine. We have clients who say they are taking their medication faithfully and the sample shows that there is nothing at all in the bloodstream. Also there are metabolic oddities which cause some people on normal doses to begin to build up very high levels of the stuff. Then they do not like the toxic side effects and reduce their own dosages until they finally forget about it entirely, and begin to have seizures again. Of course the seizures do not occur the first time the medicine is overlooked so there are no immediate consequences to remind the patient to take each dose.

One more comment on the GLC. Perhaps some medicines metabolize more efficiently over time. An individual might take the same dose daily and have his blood level go down anyway. One of the things we are trying to do in Michigan is to educate our local physicians in how to use this new tool, Gas Liquid Chromatography.

Special Education for the Epileptic:
Breaking Barriers in the System

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My presentation deals with epilepsy, education and subsequent barriers found in the public schools, and I will view the subject from the vantage point of an educator. Specifically, my remarks reflect my background as a teacher, school psychologist, administrator, and more recently as a teacher trainer.

Three major points will be covered. The first point will focus on some "givens" as a measure to those of us concerned with the foundation which establishes barriers in education. Second, emphasis on barriers in the educational setting will be noted as an actual and real threat to many educators working with children with epilepsy, and third, attention will be devoted to possible solutions.

The first given is that most teachers and educators in general have a great fear of epilepsy. In fact epilepsy provokes fear in most people, and teachers are no exception. Consequently, the first given begins and ends with the premise, generally taken for granted, that most teachers have a fear of the great unknown associated with epilepsy. Any unpleasant emotional feelings associated with the teacher's first experience of epilepsy carry over so that any stimulus associated with epilepsy at a later time, or the word itself, provokes fear.

A second given, related to the first one, contends that most teachers live with the mistaken belief that epilepsy means grand mal seizures. It may be that when the teacher witnesses the first seizure, it is usually a grand mal seizure, and therefore the mental image imprinted and left indelible in the mind of the teacher is that epilepsy is grand mal. In fact many epileptic children have petit mal seizures, which is very important for teachers to know about, but which escapes identification because it reflects more subtle symptoms. Teachers usually have little real basic information on epilepsy and even less on educational management of it.

Another important given is the probable numbers of children and adults with epilepsy. Throughout the nation an estimated one percent of the school population have epilepsy. My home state of Iowa is not a populous state but, based on these incident figures, there are an estimated six to eight thousand school children with epilepsy.

The fourth given deals with the crucial developmental periods that children pass through. Teachers normally will not see the child until he enters school, but the behavior that the child brings to school depends much upon family adjustment, the parents' feelings, adjustment with siblings, and other environmental factors. For example, a child may enter school over-protected. It is also quite likely that the parents may not

inform the teacher that the child has epilepsy particularly if medication has curbed the seizures successfully. Consequently, the first five or six years of life and the behavior and attitudes the child brings to the school setting are very important.

The second crucial age period in the school milieu is during puberty. Biologically, the stress of the first menstrual period for some girls may bring about a seizure for the first time. Teachers, principals, and other school personnel working with junior high age students need to be aware of this phenomenon.

The fifth given is that epilepsy is too often identified with other handicaps. The mental image that many people have of epilepsy is synonymous to mental retardation or mental illness probably because many people may know of a cerebral palsied child with epilepsy, a retarded child who has grand mal seizures, or an emotionally disturbed person who also happens to have epilepsy. It is true that a higher percentage of mentally retarded or cerebral palsied children have epilepsy than the non-retarded or non-cerebral palsied; however, it is equally true that epilepsy is a condition, not a disease, and that this condition is more representative in isolation from other handicaps than it is with another major disability.

The sixth given deals with modern day advances in the medical field, particularly advances in medication. The optimistic outlook in medication in the past ten to fifteen years may have given false encouragement to many educators to assume that seizures are a thing of the past. Many children still have seizures even though the number may indeed have been minimized with modern medication; some individuals cannot be helped as much as others by this means. Epilepsy is still very much with us today even with modern medical advances.

It must always be remembered that epilepsy often goes undetected. Teachers are the key to identification of possible symptoms and should refer the child for medical attention where appropriate. Epilepsy needs to be detected early and treated early. Educators are inclined to ignore epilepsy, and although they will not involve themselves as teachers day in and day out with the problem, nevertheless it is too often an omission without any involvement.

Next I will discuss some of the barriers found in education. Historically, until World War II, many large city schools provided separate special education classes for children who had grand mal seizures. Today, special education is not given to children with epilepsy unlike some children with other handicapping conditions. We do not place them in special classes any more. We do not give them white canes, we do not teach them braille, we do not provide special books, nor do we give them hearing aids. Educational goals and methods or materials for the child with epilepsy are no different from those for any other child. If the child with epilepsy has a hearing problem, he may need a hearing aid; if he is mentally retarded, he may be placed in a special education program with other retarded children, but children with a single disability of epilepsy are not generally provided special education. Special services, if any, are limited to consultation type of assistance.

As I mentioned earlier, one of the major barriers in education is fear, which the following two examples will help to illustrate.

I was attending an elementary conference held at the University of Northern Iowa about two years ago. Approximately fifteen hundred teachers were participating in the conference. One of the teachers was going from the lobby to the main area with a friend, and had a seizure in the lobby while several hundred people were milling around. Her close friends who were with her did not know she had epilepsy and did not know how to deal with it. People were frightened at seeing a grand mal seizure and thought she had a heart attack or some other medical emergency. Such alarming reactions are quite normal for most people who have no exposure or experience with epilepsy.

I had another recent experience with this barrier in a course I teach for future teachers majoring in special education. One day we were covering a unit on epilepsy and I noticed one particular student becoming quite nervous and squirmish in class. She appeared bothered about the topic and became subsequently so upset that she left the room. I spoke to her afterwards and she was most willing to unfold her story. Her first seizure occurred at the onset of adolescence and she said that her parents were very upset and never really accepted the diagnosis. She saw her family doctor and was placed on medication but she refused to accept that she had epilepsy and had stopped taking the medication over the past year. She would go back to her dorm room when she had an aura from the sensation that a seizure was pending, lock herself in the room, have the seizure, come back out, and no-one was the wiser.

Fear, and the unwillingness to face the problem, continue to plague society.

In my experience in education, one of the problems is the "over-protection syndrome" or hidden rejection, unconscious or otherwise. Often when a teacher becomes aware of a child's epilepsy he or she may tend to have the child avoid certain kinds of activities. The child may have a seizure because he faces some pressure to complete an unpleasant assignment. The teacher may reprimand a child prior to a seizure and feel guilty afterwards that she may have caused the seizure. It is quite easy to waive certain requirements for the epileptic child which normally would be expected of the normal child but actually, such over-protection is more harmful psychologically in the long run than the seizures themselves. Many children with epilepsy are not allowed to swim, cannot participate in sport,must avoid driver education, or other kinds of activities associated with physical contact, use power equipment, et cetera. If epileptic children escape academic and extra-curricular activities this becomes a real psychological or sociological barrier. Only with a valid and legitimate medical doctor's approval should any child be exempted from school activities.

Educational barriers are perpetuated when teacher training institutes fail to expose future teachers to epilepsy even though an estimated one percent of the school population have such a condition. There are four thousand elementary and secondary majors in education alone at the Univer-

sity of Northern Iowa, and only recently has the subject of epilepsy received attention. An introductory course to the Education of the Exceptional Child, 22:150, is now required of all elementary majors; a unit on epilepsy is taught in each section of this course. However, the programs in secondary education, school administration, school psychology, and speech therapy, receive no input to such an important problem. my knowledge, most training programs throughout the United States do not require some basic knowledge and understanding of epilepsy, and any input into the training programs is by chance and not design. Considerable impact can be made at the pre-service level if priority is placed on teaching teachers about epilepsy. Much can be done to dispell old myths and misconceptions if given the opportunity.

Research concerning the epileptic child in school is limited basically to surveys or interviews of parents or individuals with epilepsy. A review of the literature confirms the educational barriers, teachers' fear of epilepsy, and their inclination to over-protect.

Educational research conducted in England and in the United States, however, indicates much can be done. Experiments with teachers in in-service training, guidance and counseling have increased and changed teacher behavior positively. One research study by Caveness not directly related to education showed that over a fifteen-year span, the general public's opinion of epilepsy has shifted to a less biased one. For example, in 1949 Caveness surveyed over 20,000 people. He followed up his 1949 survey with another survey in 1964 for comparison purposes. One of the questions asked of the participants in the study was, "Would you object to your child playing with an epileptic child?" In 1964, 77 percent said they would not object while in the 1949 survey, 57 percent said they would not object. In 1964, only 21 percent thought epilepsy was a form of insanity while in 1949, 41 percent thought it was a form of insanity.

These two items from the study represent common misconceptions. According to this study, few people in the middle 1960's hold credence to many of the old wives' tales. Perhaps we have made additional growth during the past ten years but too many people are still uncertain about epilepsy.

One of the better studies conducted in an educational setting was by Bagley in England. His research involved 109 teachers, all of whom had at least one epileptic child in their classroom. Forty-three of the 109 teachers knew that one or more pupils in their classroom had epilepsy; 66 did not know this. Most teachers who have a student with epilepsy are unaware of it. The study did not explore the reasons why the majority of teachers were not informed. We can only speculate that the parents did not tell them. Other findings of this study included over-protection on the part of many of the teachers. Exemption from certain physical activities and potential danger spots such as the industrial arts class was commonplace.

Another barrier in education is that misguided attitudes so often produce a sociological and psychological handicap greater than the

physical or biological disabilities associated with epilepsy. The physical overt act of a seizure itself does not cause any emotional or learning problem but how the child and those around him feel about it can have a profound impact for better or for worse. A wholesome accepting attitude may make for a healthy child. Conversely, shame, rejection, bitterness and like attitudes breed an inclement personality in many individuals.

Most problems of handicapped children are psychological or sociological in nature. A person may have a disability and be handicapped. At the same time a person may have a disability and not be handicapped. If I were to have a car accident, for example, and lose a leg, an arm, or two legs, I would be able to teach my class and carry on my administrative duties. According to the guidelines of the Vocational Rehabilitation Office, I would not be classified as handicapped, and therefore, would not be eligible for rehabilitation services since I could carry on my job even though with greater inconvenience. It would be very much a handicap if I started drinking because I could not live with the disability, and could not get along with my family at home and my colleagues on the job. A handicapped condition results from a psychological rejection of the disability and failure to cope with the personal and social adjustment necessary. The psychological and sociological problem supersedes the major disability. How epilepsy is perceived by the child, parents, and teachers is most important.

Polar to this is the example of the Shasta Indians in California who believe that epilepsy is a cherished condition. Seizures are a rarity and are counted as a valued ability which lead an individual to positions of importance, power, and honor. The social and psychological implications of epilepsy in the Shasta society are positive.

Educational barriers to the handicapped have recently spurred a litigation movement forcing the schools to do what they have not done in the past. The handicapped and advocates for the handicapped are going to the courts not asking just for free education for all but an education commensurate with the real needs of the child. Parents are pressing charges that the public schools have failed to provide an equitable education for all children. Although the courts have generally ruled in favor of the plaintiffs, most charges illustrated the needs of the retarded and more severely handicapped individuals. Problems of epileptic people apparently have not been pronounced enough to encourage the parents to follow a similar pattern. Parent organizations for the mentally retarded and cerebral palsied have been collectively organized for some time and sway considerable influence with state and federal legislators. Where they have failed to get what they want through legislation, the courts were the logical place to seek equitable education. Parents and advocate agencies for epileptic persons have yet to show corresponding pressure to gain similar attention to achieve their goals. Certainly, the person with epilepsy is not without cause and litigation is a logical route to obtain equitable opportunities in school. The rights to participate in school sports and driver's training are classical illustrations.

One of the risks in obtaining fair play through litigation is the association of such action with militant movements. The black people want equal rights and are militant because of such insistence. Women are

more militant because of insistence for women's rights. Teachers are militant because they join unions. The handicapped are militant because they insist on equal and quality education. Furthermore they have gone to the courts to assure such a guarantee. The spin-off effect of such pressure has resulted in advocacy agencies having greater difficulty raising donations for budgetary purposes. More and more people are refusing to help on the basis that those demanding equal rights have equal responsibility and should work out the problem themselves.

Now to some solutions that the field of education may consider. Solutions are found by defining and clarifying the problems. We have identified some of the problems. The next task is accepting the problems and barriers and agreeing on a plan to correct them.

In order to eliminate the fear and misconceptions that many teachers carry throughout their teaching careers, the universities and colleges must reach future teachers through good pre-preparation programs before they go out to teach. Exposure to eliminate unfounded fear results in a gradual diminution of that fear and exposure to the truth about epilepsy during teacher training is extremely important for changing attitudes.

Some more illustrations of the results of ignorance may be in order. If a school child has a grand mal seizure periodically, it may take him out of commission for a couple of hours. Too often we react as if the child is sick and requires considerable care, yet if a child misses a few hours of school because of a migraine headache, the 'flu, or diabetes, we hardly give it a second thought. So it should be with epilepsy.

Teachers often misinterpret petit mal seizures as inattentive behavior on the part of the child. The staring or the fleeting seconds of the petit mal seizures are too often mistaken as inappropriate behavior which in the end result in inappropriate teacher behavior. The child may be reprimanded or ignored completely as a slow learner.

Psychomotor seizures can also be mistaken for pupil misbehavior. One child referred to me several years ago was known to have psychomotor epileptic seizures in school. The child would exhibit bizarre behavior. One time she stood on a lunch table and made silly kinds of movement. The teachers in the lunchroom were up in arms, pulled her off the table and sent her home. The principal asked her parents to keep her at home until she was able to behave herself. After the school received an explanation that her behavior was often typical of psychomotor seizures, she was taken back in school and got along nicely.

Good medical follow-up is extremely important. Teachers need to work closely with parents and with medical authorities. Heavy medication can sedate the child so much that he is often lethargic and sleepy and teachers can help to reach solutions to over-sedation. Teachers and parents alike must know that regularly scheduled medical attention is extremely important. For example, if a child has petit mal seizures, and perchance the condition goes untreated or is treated irregularly, or if the child takes the medication irregularly, there is considerable risk of the child having grand mal seizures at puberty.

Some solution must be found to over-protection and over-solicitation of the epileptic child. Pampering and pitying are too often commonplace. The expectations of children with epilepsy ought to be the same as any other child, except in the limited number of situations in which the child would be a danger to himself or others.

In closing I must mention the importance of including the individual with epilepsy in the team approach. Very often the person is left out of any decision concerning his own destiny. He is more inclined to be a change agent if he is given responsibility in shaping his own affairs, whereas if we do too much for the individual, he will do less for himself.

DISCUSSION

Member: I wonder if there should be a change or an addition to the curriculum, or perhaps there could be a requirement in certification through the Department of Public Instruction.

Dr. Courtnage: The answer might be to bring some pressure. It seems to be a matter of priority as far as the committees are concerned.

Member: Aren't the "school alert" kits adequate to take care of this problem?

Dr. Courtnage: If they read them. They need exposure beyond the written material, working with the problem a little bit, viewing the problem, then it rubs off.

Ms. Perrin: It is a slow process. In Nebraska, I got a lot of exposure by sending the total list of school nurses a kit. After that, I was asked to help with a great number of problems.

Dr. Courtnage: You could simulate a mock epileptic procedure.

Ms. Perrin: There is a set of slides that shows what a teacher did in a classroom. It is very good and we use it repeatedly.

Member: In Minnesota, we send out the "school alert" kits to the school principals and then follow up. We have a half-time Director of Public Information and Education who will go out and address meetings.

Member: I agree with you that this should really be part and parcel of the education of the teacher. This is just a small experience, but I am on a student health council in Detroit, and from time to time we send service indoctrinations to teachers. You have to put it basically in the education system.

Dr. Courtnage: You have to put it in on their contractual time.

Dr. Renwick: We have a naive assumption that if we explain the facts of epilepsy to teachers, their attitudes will change, but you should be aware that the opposite has occurred. Epilepsy is really a very tricky kind of disorder because there is so much emotion that just ordinary information may make things worse than before. You must give the teachers a positive role to play and show them there is something they can do.

Mr. Ferguson: The Developmental Disabilities Program does have teacher training in the unaffiliated program, and one of the objectives is to influence the change of curriculum and get away from traditional ways of training our professionals.

We may not have made much progress in that area. I'll challenge a group such as this to make the thing work, get down to the basics and get some of the research done.

Job Placement for Persons with Epilepsy

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The material I will be presenting really consists of highlights of a chapter I wrote for a forthcoming book called Epilepsy Rehabilitation which is a sequel to Total Rehabilitation. It is to be published by Little, Brown and will probably be out in September or October. The chapter is called "Job Placement and Post-Placement Services." I recognize the importance of what happens after placement has been accomplished, therefore it is hard for me to talk about job placement without adding something about post-placement services.

Proper provision of job placement and post-placement services necessitates viewing the job against the vocational goal. To settle for "just a job" that does not implement the rehabilitation plan is a disservice but we know that this happens all the time.

One must avoid stereotyping persons with epilepsy and generalizing about jobs. Professionals offering placement and post-placement assistance need to consider the idiosyncratic nature of each client and the particular epileptic condition. They must also acquire familiarity with specific jobs and job situations.

In an article on rehabilitation of persons with epilepsy, Mary Switzer wrote, "If the client is unusually sensitive to tension or anxiety, special care should be taken not to place him in a job where there are likely to be personality clashes or other sources of frustration or unpleasantness which could precipitate seizures."

Factors to be considered include closeness of supervision, the pace or tempo of the work, co-worker characteristics, and irregular working hours or excessive overtime. Work shifts can be used strategically in placing clients whose seizure-free time is predictable.

Persons with epilepsy may be especially sensitive to any of the working conditions described in the Dictionary of Occupational Titles, that is: indoor or outdoor conditions or both, temperature extremes and changes, humidity, fumes, odors, dust, poor ventilation, noise or vibration, and hazards. Noise can be a particularly worrisome factor, for at high enough levels it subjects persons with epilepsy to possible audiogenic seizures.

It is pertinent to know the content of job application forms used by different companies and the necessity for and nature of medical examinations and employment tests. If they are required, what do they cover?

Visits to job sites are more likely than printed materials to yield reliable, real-life information. The chapter in the book includes an

outline that offers a systematic approach to various physical, psychological, and psychosocial factors to be observed. Informal job analysis can be accomplished during such visits by observing work being performed and by talking with workers and supervisors.

Personal and organizational sources of information are included in the manual for the Three Cities Project of the Epilepsy Foundation. Information about jobs can also come from clients' work histories and their placement and post-placement experiences.

One placement specialist nas suggested that employed handicapped persons are willing and able to help the counselor by notifying him of job opportunities for other handicapped persons. Another counselor has organized an association of employed handicapped persons whose major responsibility is to keep alert for possible job opportunities and report them to him.

Just as job placement should meet client needs, it should also meet employer needs. After job vacancies and employee requirements have been ascertained, it is a professional responsibility to be responsive to these needs. Only qualified clients should be proposed as prospective employees. Although employers can be given no guarantee of effective performance on the job, clients ready for employment have gone through a number of "pre-selection" stages, a point that can be made with employers, including evaluation, counseling, training, and work adjustment, which the typical person applying for employment has not had.

Findings of one workshop showed that most employers contacted had limited knowledge of epilepsy, but in many cases were willing to accept the recommendations of the placement staff. A counselor can provide really more substantive information about the client's potentials for employment than is ordinarily provided to employers. That reputation can be developed. Employers viewed the counselor as an objective source of information because he was able to substantiate his statements by explaining that the client had been in the program for a given period of time and that it had been possible to observe the client's abilities on a real job.

Employers raise many objections, however, and the one most frequently encountered has to do with safety. They expect that seizures will endanger the clients themselves, their co-workers, and company property. Two approaches can be adopted to this objection. One is to cite studies showing that safety records of workers with epilepsy compare favorably with those of other workers. Employers may be impressed by the following citation of a report from the U.S. Department of Health, Education and Welfare. In Los Angeles, a machine shop employing about fifty persons, all subject to seizures and some of them not well controlled, earned a 20% discount on the workmen's compensation insurance premium because of its safety record.

It must be impressed upon employers that there is no increase in the premium on workmen's compensation because there are persons with epilepsy in the employ of the company. As with any other kind of insurance, workmen's compensation is based upon experience, and actually

persons with epilepsy and other handicaps are more cautious. The safety factor is higher, the accident rate is lower, and so in practice, so-called handicapped employees on the work scene tend to reduce the accident experience and the rates. This particular machine shop in Los Angeles earned a 20% discount on its workmen's compensation insurance premium because of its safety record.

A study based on New York State Workmen's Compensation Board records showed that compensated industrial accidents resulting from seizures were less than half those resulting from sneezing and coughing. Evidence of this kind can be impressive in producing job placements for persons with epilepsy.

The other approach to the objection regarding safety is to reduce hazards to a minimum by making appropriate placements. Here is the conclusion of an article by Wallin:

> "Epileptics should not be placed in hazardous jobs, such as driving trucks or automobiles, piloting airplanes, operating elevators or cranes, operating moving machinery, working near hot boilers or hot metals, and the like."

He goes on to say:

> "There are thousands of non-hazardous jobs available at every level of competence and interest for qualified workers of all kinds, including epileptics of either sex."

Studies by the Veterans Administration and the Epilepsy Foundation have shown that persons with epilepsy can be placed in a great variety of jobs.

In addition to objections regarding possible accidents, and claims for workmen's compensation, the question of use of health services is often raised by employers. Numerous studies have shown that in this area, too, disabled workers, including those with epilepsy, and non-disabled workers, are comparable in use of health services as well as in frequency and severity of accidents. Health insurance rates are based simply upon the sex and age composition of a company's employees, workmen's compensation insurance rates upon a company's or an industry's accident experience and its work hazards.

Resistant employers manifest vague expectations concerning decreased productivity, adaptability, group morale, and increased absenteeism, turnover rate, and lay-off difficulty. They feel vaguely that there is something not quite right about hiring such people, that something will go wrong, it will cost more. Effective job placement counselors break through the vagueness of these objections, and get down to specifics which they can then attack with convincing arguments.

In one study, employers rated their epileptic employees equal to non-epileptic workers with respect to productivity, absenteeism, cooperativeness, and popularity. In other studies, absenteeism and turnover

have been shown to be lower, with dependability and loyalty higher. It is important to realize that it is the way the findings are used that can make them effective or not.

Employer resistance can be counteracted by arranging a subsidized on-the-job training opportunity for the client. The chapter in the book describes four types of on-the-job plans, pay and supervision being variables. Usually the supporting agency provides part of the pay so that the employer hires employees without paying them the full wages, but as time goes on the contribution of the supporting agency goes down and the employer's contribution to pay goes up, and the other variable, supervision, is greater at the beginning, diminishing as time goes on.

This, therefore, is an opening wedge for many kinds of persons with disabilities, including epilepsy. Through on-the-job training, a client can demonstrate the findings of research by his performance as an employee. That is the basic difference between the research findings, findings of studies and surveys, and actually getting a person into a situation where he can show that he can perform the work of an effective employee.

Bernie Posner, Director of the President's Committee on Employment of the Handicapped, reported on an experience in New Mexico in the National Spokesman in January 1972, where it was found that employers' guilt feelings sometimes made them warmly cooperative, even if they did not actually offer job placement.

One of the major recommendations of Harry Sands' study of the attitudes of policy-level executives responsible for hiring personnel toward employing persons with epilepsy was to "involve executives in public education programs rather than have them be passive targets."

Experienced placement specialists commonly favor policy-level executives as the first employer personnel to approach in job development. Top-level personnel are in a position to pave the way down the echelons to the medical examiners, the actual hirers, foremen or supervisors, and other employees.

Mayors' and Governors' committees are additional ways of involving employers. The most effective way, however, is to involve them on a local committee like the ones used for employment of the so-called mentally restored. The committee functions as a form of group consultation, assisting job seekers to take stock of themselves and their job prospects. They feel they are being used as consultants, not merely being sold something.

Being exposed to persons with epilepsy is often enough to remove the stigma. This has happened with ex-mental patients, and could well be applied to persons with epilepsy.

The question often arises, is it best to go to small employers or large corporations? Both approaches may be used. It was found in the Three Cities Project of the Epilepsy Foundation that clients were easier to place in small to medium size firms with less structured personnel policies. On the other hand, there is evidence of many large companies which have successfully employed handicapped persons.

The Federal Government, the largest employer in the United States, is already involved in programs providing job opportunities for disabled persons. A U.S. Civil Service Commission report highlights a significant development. An alternative method for employing the severely disabled has been established, a process which provides for the Veterans Administration or a state vocational rehabilitation agency to certify a severely handicapped individual to a certain position in lieu of his meeting the competitive qualifications for that job. Under Ed Rose, the U.S. Civil Service Commission has broken many barriers for the person with mental retardation, for persons who are blind, and for persons with epilepsy.

The writing of a rehabilitation plan is too often taken to imply that a client is ready to implement the plan. However, placement is contingent upon his placeability, his ability to gain employment; placement is not a passive process. There is an important distinction between employability and placeability. The state DVRs always have a large category "ready for employment." They are employable if anybody would give them a job, but they need to be helped to become placeable.

A primary precept of placement is that it is best for clients to find their own jobs. For one thing, a client who finds his own job may experience enhanced self-esteem. He may also be called upon more than once to find his own job.

The problem solving learned in effective counseling needs to be paralleled in effective placement. Confucius said: "Give hungry man a fish, and tomorrow he will return for more. Teach hungry man to fish, and he will feed himself for evermore." In a project at the Kenny Institute on employment problems of epileptics, it was reported, "Instead of ... having trained placement personnel make initial contacts with prospective employers, it was found that the most effective ... method was to counsel the patient" to place himself.

Effective job placement requires effective job-seeking skills. The Michigan Epilepsy Center concluded that, rather then "inadequate seizure control and negative attitudes of employers ..., it became clear that occupational factors such as employment motivation and job seeking skills played certainly as important a role in job success ..." A multiplicity of job leads must be developed and a variety of job-seeking techniques utilized.

Clients may need assistance in writing letters of application, preparing rēsumēs, requesting recommendations, organizing personal records, assembling portfolios of samples of their work, completing applications, taking tests, and maintaining files of prospects and progress. For the ordinary job seeker it is almost a full-time job in itself.

In the development of interview skills, role-played job interviews can provide awareness of employer expectations, and the client is enabled to present his capabilities. An important part of preparation through role playing is role reversal, in which the client playing the employer gains sharper perceptions and insights into the other person's position.

A question which constantly arises is "to tell or not to tell?"

There is evidence that about half of clients with epilepsy tell employers about it. Forrest found that those who told "encountered great difficulty in securing a job... however, when these epileptics finally secured work, they had less anxiety and ... fewer seizures on the job. When seizures did occur, the clients were less likely to be fired ..."

One variable entering into the client's decision is the extent to which his condition is controlled -- freedom from seizures, frequency of seizures, time of occurrence, aura or other warning. Another variable appears to be the extent to which he is controlled, overtly or covertly, by his counselor. Some counselors over-generalize that "honesty is the best policy" to clients for whom it may be poor practice.

The dilemma is poignantly pointed up in a publication by Dorothy Thompson of the President's Committee on Employment of the Handicapped in a discussion of placement problems of the so-called mentally restored. A former patient said, "After you've told the truth X number of times and been turned down X number of times, you have to ask: 'What do I really want? A job, or a reputation as George Washington?'"

Forrest also reported that those clients not divulging the presence of seizures did get jobs more quickly, but seizures on the job seemed to occur more frequently in this group, and he reported in every instance that when a seizure did occur on the job, the epileptic was fired. Some who had seizures on the job felt their anxiety about being discovered to be epileptic helped to trigger the attack.

The employer is another variable. Some employers discharge such employees automatically; others overlook an employee's epilepsy once he has proved himself an effective employee.

"To tell or not to tell?" is not a question for counselors or placement personnel to answer. They can help a client answer the question for himself by discussing all the factors and information germane to his situation, and the possible consequences of either decision. If the decision is to tell, the counselor or placement person proceeds with his customary honesty in relation to employers. He cannot conceal a client's disability but he can avoid diagnostic labels and present the client in a positive light. A similar approach applies to the self-placement of clients who choose to tell.

If the decision is not to tell, the counselor or placement person cannot tell employers without the specific consent of the client. Without such consent, the only course for the client is self-placement, which does seem to have certain advantages. A client who first chooses not to tell may later decide to tell his employer or supervisor or his co-workers.

Individual counseling is economically and effectively supplemented by group counseling in preparation of clients for placement. Group counseling was successful in the Three Cities Project of the Epilepsy Foundation. Since many job-seeking dilemmas pertain to persons without epilepsy, other clients may be used to bring added perspective to a group.

In discussing post-placement services, I use this term in preference to follow-up, to emphasize the services many clients still require after placement. Follow-up is frequently done to obtain impersonal data reflecting program effectiveness. Post-placement services are provided to ensure and enhance the effectiveness of prior assistance to clients.

Post-placement assistance overlaps placement assistance and serves not only clients but employers, counselors, and agencies as well. The last contact with the client during the placement phase could include the nature and purposes of post-placement services as well as the client's perception of his anticipated needs for these services. Discussion of anticipated needs in itself sometimes helps to obviate them.

A post-placement plan can be arranged at that time, setting a date for a subsequent contact. The Three Cities Project findings stipulated contacts with clients "at minimum intervals of one month, three months, six months and one year after placement." Common post-placement practice calls for a contact within the first month and regular contacts every month thereafter. Initiation, frequency, and overall duration of contacts would depend upon the characteristics of the individual client and of the particular job. Where client dependence is a critical factor, the schedule of contacts might represent a weaning-away process. Personal visits or telephone calls are made to the client, the employer, or both. The prior decision to tell or not tell would be a major determinant.

Visits to places of employment must be planned to avoid disturbing the employer's operation or the employee's work. Employer approval of such visits is necessary, as is client's consent regarding post-placement interviews with employers. As appropriate, clients may also be visited at home, particularly if the family needs to be brought into the picture.

Client visits to the agency during non-work hours avoid the possible disturbance at the work place and perhaps even risk to the client's job. These visits may be arranged at special times to accommodate clients if counselor work schedules are adjusted. Regular agency office hours beyond the usual day might be an added convenience to clients.

Many clients require and employers appreciate assistance at the beginning of a job. As reported by the Three Cities Project, "The build-up of anxiety, especially on the first day of a new job, oft times precipitates a seizure. A guide to placement of Neighborhood Youth Corps enrollees with epilepsy emphasizes that, once a job placement has been accomplished, the first step is to introduce the youth with epilepsy to his job. Duties and procedures should be clearly outlined. New persons should be introduced. Some clients benefit from a "buddy system" in which one employee assumes a supportive role. Orientation may be needed in such matters as rest periods, reporting absences, use of telephones, and take-home pay -- the things new employees are not familiar with. Unrealistic expectations are common in regard to pay raises and promotions.

Clarification of possible causes for complaint can counteract a client's inclination to quit. Aside from the condition of epilepsy, we know that many young people quit jobs very quickly, when the first pay-check comes around and the take-home pay is not what they expected it to

be, or three months have passed and they have not been promoted. The person with epilepsy who has had little or no experience with regard to employment needs to be provided with realistic expectations of his employment.

In providing post-placement services, effective inputs are elicited as needed from clients themselves, their employers, and family members. Questions that might be asked of clients include: is he still on the job? Is he working at the job on which he was placed? Sometimes between the point of placement on a specific job and the point of follow-up it is found that the employee is working at something else that may not be in line with the vocational plan, therefore: is the job in keeping with the voacational plan? Is his condition medically and psychologically stabilized?

Questions that might be asked of employers might be: is the client a satisfactory employee? Are there problems affecting his work efficiency or work adjustment? Does he need additional training to improve skills to merit advancement?

The family members might bring added perspective to these questions: does the job appear physically fatiguing, psychologically lacking? Does the client have social and recreational outlets? Is the client growing toward optimal independence? Are client and family at odds on any important matters?

This basically concludes the highlights of the chapter on job placement in the book I referred to earlier.

DISCUSSION

Member: On the question of to tell or not to tell, how much of what you said is different from what you should do if a person is mentally ill or alcoholic?

Dr. Sinick: These are basic guidelines. I don't think any general response to that would be useful to you in your specific dealings. I think basically the generic approach would be applicable.

Dr. Rennick: On that same question, if the client and you or the rehabilitationist decide not to tell, then the rehabilitationist withdraws his services and the client is on his own?

Dr. Sinick: If the client does not want to tell, he may have to engage in self-placement basically, but it doesn't mean that the counselor's services are withdrawn.

Dr. Rennick: Direct contacts with the employer cannot be made by the counselor?

Dr. Sinick: They could be made but not on the basis of telling if the client does not want to.

Dr. Rennick: So you are advocating the client could become an employable individual with the company without telling.

Dr. Sinick: The job development services for the individual would go on with respect to different employers, but that issue is really an ethical one controlling the conduct of the counselor.

Opening Remarks

Arthur Petry
Regional Manager
Epilepsy Foundation of American
Chicago, Illinois

Probably at some moment in the course of this conference you wondered how you got here, and perhaps even why.

It all started about two years ago when our office first opened. Among the first people to stop by were some delightful people from DDA, and as I was in an argumentative mood that afternoon, I said, "I don't think epilepsy is getting its fair share. As far as I can see from looking over the grants, all you people trained in other disciplines are taking all the cream." The answer was, "That is probably because we don't understand epilepsy." After a little more discussion I was asked, "Will you teach us?" My reply was, "Why not? You have the money, we have the skills." And that started this particular conference down the road.

The meeting was designed for a select audience, the top administrators of the Developmental Disability Act and key people from the Department of Health, Education and Welfare, vocational rehabilitation people, those persons who were in need of knowledge of all the disciplines involved in the DDA Act at the state level.

You realize from what has been said here the tremendous challenge educationally that the whole spectrum of epilepsy faces. We started down several paths. We encouraged our local directors in EFA to contact and become acquainted with the DDA people at the state level, trading information and knowledge with them. We encouraged them to get involved and seek personal guidance from DDA in the preparation of grants. We urged our people on the state level to develop in concert with vocational rehabilitation people and those in DDA and other governmental agencies, training sessions at the state level. A number of excellent ones were carried out. Indiana is a good example, and Ohio, and Ms. Perrin had a first class meeting in Nebraska; others also have taken place.

Collectively, we wanted to bring everyone together and exchange ideas. Therefore, from our standpoint we did not urge a great number of EFA people to come to this particular meeting, because we wanted to train others.

At this point I want to thank Bill Ferguson and Bob Vogt for this wonderful training session for the people in my region. I have five brand-new directors, and I was wondering how I could get them all together for a training session. All five of them are here, they have been here for two days, and are getting the orientation I could not possibly have paid for.

I also want to thank wonderful people like Marcile Perrin and Judith Lester, whom you have heard from. They were the advance "apostles" who helped train me, and in turn these new directors are taking their positions on the line. Hopefully, they will take away a great many things. From my standpoint, therefore, the meeting has been an outstanding success.

Perhaps the participants might be concerned about the rather small audience. At the state level and in other areas, led primarily by consumer oriented people, we have developed attendances at open houses of 450-500 people, but that is encompassing everyone. This was designed to be a select training session. We may have one for the DDA people sometime, but that is in the future.

In view of the fact that we might not get the ideal type of audience, a substantial amount of money was budgeted for the conference proceedings to be completely recorded, and this is one of the major byproducts of the meeting. Subsequently the transcript will be edited and disseminated in the form of a monograph, which will be available through the directors' offices officially on a regional level, and to select audiences determined by you. So it will be a permanent reference for this meeting. We plan to mail the monograph to each of the participants, after which the other tailored distributions will go out to other sources.

I challenge those of you who have been here two days to match the scope of this conference, or attempt to exceed the collective talents that have appeared here.

At this point we are going to throw open a freely structured discussion that will involve the participation of the audience and a panel consisting of those leaders responsible for this meeting. They are Mr. William Ferguson, who is the DDA Regional consultant from Kansas City, Mr. Robert Vogt, who with Mr. Ferguson has been responsible for the financial help, and also for much of the guidance and enthusiasm to carry it out, and Mr. Thomas Ennis, EFA Executive Director.

We will throw the session open and ask you where you think we ought to go, how best to channel the information we have learned here, how best to follow this meeting up, or perhaps to identify a set of operational priorities that can be transferred back to the states for consideration.

Discussion

Panel: Epilepsy Foundation of America

Thomas Ennis
Executive Director
Washington, D.C.

Arthur Petry
Regional Manager
Chicago, Illinois

Department of Health, Education and Welfare

William Ferguson
Developmental Disabilities Consultant
SRS, Region VII
Kansas City, Missouri

Robert Vogt
Developmental Disabilities Consultant
SRS, Region V
Chicago, Illinois

Mr. Vogt re-stated that the original emphasis of the conference was to give information and visibility on the epileptic and the programs available and to bring together the decision-makers responsible for planning and evaluation of state programs, and ask them, "What is going on in epilepsy?" A member of the audience had suggested that the relatively small attendance might be a result of the large number of activities taking place elsewhere, and that a number of smaller meetings over a wide area might be productive. Mr. Vogt replied that for wider coverage they would have to depend on the monograph and the exchange the participants would have with others, relying on their expertise and community organization to contact and become part of the DD planning bodies. He recommended that the DD Council in each state attempt to duplicate the conference to some degree on a local level.

Dr. Rennick asked if the national or regional DD, or the EFA, would endorse the monograph, so that when it was distributed to state councils and council members it would have an official stamp. Mr. Petry replied that its only authority would be that it was carried out under the auspices of Regions V and VII. He said that fourteen hundred copies would be printed in the first instance. Mr. Ferguson affirmed that the important thing was its distribution. As the four states in Region VII had not only DD state councils, but had also established regional councils, he thought that would be a good network for reaching local committees.

Mr. Vogt thought the importance of the meeting was the kind of fallout to be seen in the basic planning structure in the state. He asked how much further it had to be taken at the state or federal level to allow state planners and staff members to have the information they needed to plan.

Dr. Rennick thought that although information had certainly been forthcoming from the meeting, it was not always the kind needed for planning. He pointed out the necessity for facts and figures about regional and local problems, and asked how much effort was being made to get this under DD auspices. He cited an instance in Michigan where they had tried to conduct a physician survey on a small amount of money, and the results had been negligible; it had been a waste of time. He emphasized that it was hard to get basic facts about epilepsy because of the problem of the "hidden families" who did not want to give out information, and the doctors who did not want to violate their families' confidence. In his opinion, the hard questions that always had to be faced were, "Can you demonstrate that you need services? What kinds of services are you trying to provide? How many people are not

getting them?" He said that people at political levels who decided major contributions to programs had flatly said to him, "In Michigan you don't have an epilepsy problem," and he had to agree that no facts and figures were available to prove differently.

A member of the audience described a discussion of epilepsy, mental retardation and cerebral palsy which had been put on in the State of Wisconsin a year previously, through the Coordinating Communication Center, at which participants described what the disorders were and what were some of the needs. Important services helpful to the epileptic had been defined as referral, information and protective services, but it appeared that there was a need also to define terms.

An example was given of a state law which stated that everyone with epilepsy must report to a physician, and physicians must report to the Board of Health, yet in that state not one individual had been reported in the last ten years. Could the difficulty again be in the meaning of the term "epilepsy?"

Mr. Ennis agreed that the legal definition was a problem and said that on the national level they were constantly trying to gather more accurate epidemiological data, which was very difficult to obtain. On a local basis it was almost impossible to ascertain how many people were institutionalized with epilepsy even in a relatively small state. As well as not reporting to a physician, they did not report it to schools, which indicated a very heavily hidden population. Epidemiologists working with the Foundation nationally and on the professional advisory board used a figure of 2%, which some thought was high; however, some well-known epidemiologists and biostatisticians put the figure as high as 4%. Dr. Kurland of the Mayo Clinic had estimated the number to be three-quarters of 1% but the survey on which he based this figure was done in Rochester, Minnesota, many years earlier, in a farming community with few minority groups, therefore it was probably atypical. There was the additional problem of individuals with all three developmental disabilities.

Mr. Ennis also pointed out that he had noticed at meetings that very gross generalizations were made, assuming that data on other diseases, disabilities and disorders was factually better; this was not so. Cardiac information, for example, was also very difficult to ascertain. He quoted a case where physicians in Virginia state hospitals had asked how many individuals were hospitalized in the State of Virginia with epilepsy as a primary disorder. Nobody knew, but neither did they know about the numbers of blind persons.

In Wisconsin there seemed to be some potentiality to extract some of this data and also the kinds of services needed. It was mandatory for a physician or anyone else with the knowledge to report to the public school even a baby suspected of a potential disability. There was also a state law requiring that a group of counties plan, provide and evaluate a full range of sixty service elements for DD. Part of the guildeline was that a county indicate those they found to be epileptic, mentally retarded, or having cerebral palsy, what services were being provided, and what were the gaps. However, the speaker also wondered if the problem would end up being one of definition.

Mr. Ennis stated that the legal definition of epilepsy was more complex than the definition of mental retardation or cerebral policy. In some international classificatio , certain forms of migraine were classified as a form of epilepsy. He asked if that would mean a child with severe migraine headache would be eligible for state services if the legal definition included that. He cautioned that if one defined too carefully, there would then be the problem of exclusion.

Agreeing that definition was important, another member felt that in Wisconsin, because the State Act followed the federal definition, the problem would be, who was actually going to provide what services?

A member asked how one could obtain the names of the people they knew did have seizures. In Nebraska, they were involved in information referral in six regions across the state, but although the State Department of Special Education, as the result of a year-old survey, had in its computer all schoolchildren by name with any kind of disbaility, they could not get that information from them. The speaker wondered how, if they did get information by name or some other way, they could be sure they were not counting them twice. Mr. Ennis said that in the State of Maryland, the local Civil Liberties Union had blocked that kind of data in counties for use in the school system, maintaining that it was unconstitutional to gather it unless one had a specific purpose in mind.

The possibility of duplication of numbers was stressed; for example, those listed in the MR program were also listed in the Special Education survey; they could not be counted unless they were identified. The member from Wisconsin thought they could be identified by who was responsible for what service, and said that in that state it was a cooperative venture in that there should be no difficulty deciding whose numbers were whose, the dividing line being confined to who was responsible for providing what services.

Dr. Rennick thought that as the state had the information in the computer banks, a case could possibly be made that it therefore had the responsibility to conduct a survey and retrieve the data.

Mr. Ferguson reported that each state was working on this. Whereas the data had been generalized in the past, now it was becoming more exacting. Some states in his region were considering certification for eligibility for DD following the definition given in the regulations. He thought that possibly in the future they might do with DD what they were doing in rehabilitation. Dr. Rennick said that would certainly bring out the hidden nature of the disorder. He described a second coverage law in Michigan for which an epileptic patient could be certified, and any company employing such a person did not then have to worry about any workmen's compensation following seizure. One thousand certifications had been issued in the whole of Michigan, and the authorities looked sceptically at them, yet he estimated that there were probably fifty thousand employable persons with epilepsy.

Several members reiterated that one had to demonstrate a need before anything could be started, yet once a clinic was established, people came "out of the woodwork". Dr. Rennick suggested pilot projects be started which would be supported as they attracted customers.

Mr. Ferguson moved the discussion on, emphasizing that whatever rough data was available must be used. He asked what was the most emergent problem to be followed up from the conference.

The general opinion was that public information was one of the crying needs. Mr. Ennis agreed and said that the national professional Advisory Board and the EFA Board of Directors felt it to be the number one priority. Again, he pointed out the vicious circle of more money being needed to provide more information. The law did not exclude public information; it just had a low priority the way it was written.

One of the members described the use of DDSA funds in Marion County, Indiana, to establish an office where there had been no public information at all. DDSA provided a three-year grant just to establish the office, and from that, they now had a speakers' bureau, a parent group, and a complete social program. They also put money into sophisticated equipment at the medical center and were considering supporting the chemical laboratory. She spoke of a unit where parents could drop off a urine specimen for urinalysis on a weekend and where New Castle State Hospital could fast-freeze it from the epileptic hospital and send it in. DDSA funds had paid for this equipment. She stressed the care they used in proper expenditure of the money, and that as a result, leftover funds were sometimes received from DDSA. In spite of the low priority, Indiana Department of Mental Health was very anxious that epilepsy and cerebral palsy and disorders other than mental retardation should be included; their first grant on autism was prepared. She recommended that the national and regional people let the local representatives know that they could contact their DDSA consultants for help in at least writing a grant request.

Ms. Perrin complained that so much leeway was given to the state council itself in her area that they were never allowed more than a one-year grant. That usually started when the year was one-quarter over, therefore they operated for eight to ten months and then it was over.

Mr. Vogt asked what was public information -- was it a training session, and if so, whom were they going to train? What kind of end product did they want? He thought that although it was attacked on all fronts, by training professionals, in inservice training, spot radio announcements, meetings with employers and people in school systems, the term "public information" did not seem to be deep enough.

Dr. Rennick thought the type of public information that was really lacking was the kind focusing on overcoming stigma. A member expressed the opinion that a way should be found to contact the individual concerned, the epileptic himself, and educate him. Another member remarked on the reluctance of individuals with epilepsy to come forward, as in the study done recently by the Rehabilitation Institute of Chicago, unless specific services were offered. They did not want to be guinea pigs.

Mr. Ferguson said that the DD councils were mandated to disseminate information, also the University Affiliated Facility Program. Any kind of information dissemination, film and media production, pamphlets, and the like, were all eligible as a cost factor under the DD program. However, one little report could be called disseminated information, but it might just be a report to the Secretary or the Governor. He said that states had

started developing newsletters, and although there were arguments for and against them, they did reach many offices, including some of the physicians involved and the consumers. He was hopeful that they would reach some of the legislators who sometimes operated in the dark.

Dr. Rennick suggested that the main emphasis from the meeting was that epilepsy had been demonstrated to be a special case requiring early identification and intervention in the psychosocial area; that it was more necessary than in mental retardation or cerebral palsy in order to head off many problems which might develop later. He thought that information could be offered to someone going to a facility and identifying himself as an epileptic. He stressed that attention be paid to those with epilepsy on an individual basis, as to the type of seizure, how it affected brain function, the family, and schooling. He further suggested there should be some place where a physician could refer his patients for further explanation and help. In answer to Ms. Perrin, who wondered how one could encourage physicians to do that, he suggested starting an agency they could respect.

Mr. Ferguson thought that lack of confidence could be overcome by taking a hard look at the public information system and process. In some states the Governor's Office did not want people interfering with the public information area, even for an agency program, but it did not mean that the state council, for example, could not contract with the Rehabilitation Institute of Chicago, to publish an informational document as it pertained to Illinois. Another possibility would be to contract for it with a reputable commercial or university media center. He thought it was often more effective than trying to do it on a national level even if it proved more expensive.

A member from Wisconsin reported that that state was developing a film related to what each of these areas was, broken out of which would be some TV spots. In view of what Dr. Rennick had said earlier about the results of increased research and education being more negative than positive, the member wondered how much work in that area was really needed. Another member thought that if epilepsy had as much radio publicity as VD was currently receiving, the results might be productive.

The public whould be asked to evaluate what was being done; feedback must be obtained on the effectiveness of the material from the people who received it. Dr. Rennick, however, thought it was hard to find out how the material affected public attitudes and their readiness to act.

A member wanted to know if educators really knew what the needs were and asked had anyone applied any pressure to the schools, saying, "You have a responsibility here."

Work in the MR movement in Minnesota was described where a consumer panel of retardates had been sponsored. In two years the panel had made fifty visitations to various types of groups, on both the regional and national levels. Since the public had heard the retarded people describe how they felt and what services they thought were needed, there were very few problems now in that state in having local zoning councils and other groups open up group homes and other facilities. In Minnesota, epilepsy had always taken a back place, but there had been a public information

seminar where an epileptic person had been on the program. That individual had changed more attitudes than any of the professionals on the program.

In summary, Mr. Petry asked, "Where do we want this conference to go? If we decide that, then conceivably, we will develop some form of measurement."

They had all agreed that public information was a priority. They had been interested to hear descriptions of specific systems members of the audience were concerned with.

He emphasized that one of the keys to the success of the conference was input in the names of select people to receive copies of the monograph. That would require coordination between his office and the regional offices and between Mr. Vogt and Mr. Ennig. Members of the audience would be alerted when the material was ready and then the organizers would begin an inter-communication system to make an evaluation of precisely what was happening.

He recommended that on their return home, members should get a reaction and a feel from the dissemination of material supplied to them at the conference, then through the communication linkage established through their going back into the field, a cross-reference would be available as to whether anybody used it, and if they did, was it helpful? If it were not helpful, they would be able to find how it fell short. He asked that everyone concentrate on trying to evaluate the effectiveness of two well-spent days reinforced by action in the field.

He hoped that they could return at a later date. Mr. Ferguson and Mr. Vogt were considering a follow-up to the conference with the possibility of inviting representatives from other groups to point out their concerns, and also describe what they saw in their jobs in relationship to epilepsy, and how to make it more visible.

In closing, he thanked all participants for coming and contributing their time. He pointed out that nothing worked without the mechanics of organizing, reporting, and disseminating the findings of a conference, and extended particular appreciation to Dr. Olson and his staff of the Rehabilitation Institute of Chicago for the outstanding job done and the excellent facilities provided.